

**ACTING ON RIGHTS:
THE WOMEN AND HIV/AIDS LEADERSHIP RETREAT
6-8 JULY 2005, YALE LAW SCHOOL**

Acknowledgements

As the *Barcelona Bill of Rights* sets forth, because gender inequity fuels HIV/AIDS and HIV/AIDS fuels gender inequity, it is imperative that women and girls speak out, set priorities for action, and lead the global response to the crisis.

We firmly believe that with greater communication and coordination diverse communities committed to addressing gender equity, human rights, and HIV/AIDS can build a robust movement for real change.

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I am grateful to all of the participants for giving of themselves so passionately; for sharing their perspective and experience so honestly; and for traveling such great distances to be partners in this undertaking.

It is a privilege and an honor to collaborate with such extraordinary leaders to address the most critical and wide-sweeping human rights challenge of this time.

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*Please note that the views expressed in this report do not necessarily reflect the views of individual participants or of the supporting institutions.

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I. Executive Summary

In the global response to HIV/AIDS, there has been a stunning and pervasive failure to acknowledge and address one, if not the, primary determinant of the crisis. Gender inequity is the fatal reality that fuels and is fueled by this pandemic. It is our mission to have the global community acknowledge and redress this failure.

We see four critical gaps in the global response to women and HIV/AIDS: 1) the failure to consistently acknowledge women's leadership and participation (especially that of women living with HIV/AIDS) as an essential solution; 2) the failure to draw together diverse communities with overlapping interests; 3) the failure to keep controversial and sensitive rights issues on the table; and 4) the failure to meaningfully link the global with the local.

The July 2005 Women and HIV/AIDS Leadership Retreat, held at Yale Law School in New Haven, Connecticut, USA, was a unique and significant opportunity to advance gender equity in HIV/AIDS through strengthening women's leadership; building bridges between diverse communities; focusing on controversial and sensitive rights issues; and identifying mechanisms for meaningfully linking the global with the local.

Building from the *Barcelona Bill of Rights*, the retreat focused on the three interrelated themes of 1) human rights and ethics; 2) linking reproductive and sexual rights with HIV/AIDS; and 3) gender equity in treatment, care, and support. We addressed some of the most pressing human rights concerns in the context of women and HIV/AIDS such as reproductive choice; funding conditionalities; and gender equity in access to treatment, care, and support. We also set a positive agenda for advancing human rights as a form of HIV/AIDS prevention.

Through the work of the retreat, we identified two overarching needs and mandates for our collective efforts – one of indivisibility, intersectionality, and independence; the other of bridging policy, advocacy, and research.

Participants included persons living with HIV/AIDS, community based leaders, advocates, researchers, lawyers, physicians, and service providers. Leadership and participation by women, especially women living with HIV/AIDS, was a defining element of this gathering.

Ipas, The Mirembe Project, the Center for Interdisciplinary Research on AIDS, the Open Society Institute, and the Yale Law School supported the retreat.

The outcomes of the retreat included:

- the development of ATHENA, a network to advance gender equity and human rights in the global response to HIV/AIDS;
- an operational and governance structure for this emerging network;
- a policy analysis/issue brief in the three focal areas of 1) human rights and ethics, 2) linking reproductive and sexual rights with HIV/AIDS, and 3) gender equity in treatment, care, and support;
- a research agenda for women, human rights, and HIV/AIDS issues;
- a campaign proposal on the right to know and have for women and HIV/AIDS;
- a project proposal for the development of a gender equity gauge in HIV/AIDS; and
- an international working group to coordinate with the Blueprint for Action on Women and HIV/AIDS in Canada in planning for the International AIDS Conference in Toronto, 2006.

II. Retreat Overview

Background

The Women and HIV/AIDS Leadership Retreat was an important opportunity to build alliances, discuss regional priorities, and determine pathways for action to address critical gaps in the current response to the global HIV/AIDS crisis. On-going dialogue and related civil society initiatives at the Durban International AIDS Conference in 2000, the United Nations General Assembly Special Session on HIV/AIDS in 2001, the Barcelona International AIDS Conference in 2002, the Bangkok International AIDS Conference in 2004, and the Commission on the Status of Women in 2005 highlighted the need for a strategic retreat to consolidate and coordinate efforts. The individuals who shaped this retreat, launched the related series of HIV/AIDS, gender, and human rights initiatives, and participated in this evolving, multi-year dialogue represent different communities of practice, diverse geographical regions, and distinct professions. The binding characteristic is that all share a commitment to uncovering the gendered dimension of the HIV/AIDS pandemic, and to using a human rights framework to both understand and address its impact.

Growing from the history of Women at Durban, Women at Barcelona/Mujeres Adelante, and Women at Bangkok, the retreat was organized to provide a structured space for dialogue and planning among this vibrant and diverse group of participants. Community based women leaders in HIV/AIDS, service providers, academic researchers and scholars, human rights lawyers, feminists, sexual and reproductive health and rights advocates, and non-governmental policy and research professionals were brought together specifically to identify and strengthen the intersections between these communities. The retreat was designed therefore to examine our respective strengths, limitations, and desired outcomes; to define shared terms; to build a joint platform; and to plan together for coordinated activity in the future.

Retreat preparation

While the focus of the retreat built upon conversations held over a several year period, the decision to hold a planning retreat was solidified in the spring of 2005. Animated brainstorming sessions, parallel to the Commission on the Status of Women in March 2005, underscored the importance of increased coordination. A retreat planning session hosted by the Open Society Institute in early June 2005 finalized the plan. Summaries of these meetings are available upon request.

In an effort to ensure active participation and an informed exchange of ideas, the retreat organizers worked together with the participants to create the agenda, and to develop working groups prior to the meeting. Three core areas of interest were identified prior to the retreat to provide a vehicle for substantive conversation, the production of briefing papers, and the formation of the working groups. The interrelated themes were: 1) human rights and ethics; 2) linking reproductive and sexual rights with HIV/AIDS; and 3) gender equity in treatment, care, and support. Briefing papers on each related theme are included in the appendix.

To further the exchange of ideas prior to the retreat, participants completed questionnaires that were designed to elicit priority issues for discussion and action, as well as to identify skills, resources, and institutional affiliations. Recognizing that participants represented a wide range of professional backgrounds, geographic regions, and analytical perspectives, it was

important to highlight as many overlapping interests and complementary skills as possible before the retreat so as to make use of those synergies wherever possible.

Finally, given limited resources, the retreat organizers made every attempt possible to ensure diverse representation. Individuals from Bolivia, Spain, South Africa, Thailand, Uganda, and the United States participated (individuals from Argentina, Venezuela, India, and Canada were unable to attend due to visa and/or travel difficulties). There was far reaching experience in work at the community-based, national, regional, and international levels. Leadership and participation by women, especially those living with HIV/AIDS, was a defining element of the retreat. A list of participants is included in the appendix.

Retreat Process

The retreat took place over a 2 ½ day period, from the 6-8 of July, 2005, with an informal dinner for international participants on the evening of 5 July 2005. The retreat was organized as a series of participatory, working sessions that built upon each other. While the retreat organizers played a key coordinating function, all participants took an active leadership role. As noted, the agenda was crafted through a shared process prior to the retreat, and it was reviewed together at the outset of the retreat. Modifications were made during the retreat itself to accommodate shifts in priorities. Individual participants rotated through the role of ‘facilitator’ during small group and larger group discussions. In addition, a professional facilitator was hired to work with the retreat organizers in developing and finalizing the retreat structure, and to assist in the moderation of Day One. Ms. Claudia Liebler, an organizational development professional with over 25 years in the international development sector, worked with the retreat organizers to ensure that the sessions were designed to meet stated objectives of building group identity, clarifying a collective vision, and developing an initial plan to execute that vision.

Sessions Summary

Meeting minutes are included in the appendix.

Day One –

- **Introductions, group-building, and retreat expectations.** The morning sessions were interactive and designed to assess why we were each at the retreat, and to share with one another our core commitments. We also discussed what we expected to gain from, and contribute to, the retreat experience.
- **Framing the conversation.** In order to place the work of the retreat in context, we reviewed our history of working together and reviewed the conversations leading up to the retreat.
 - a) **From Amsterdam to Durban, From Barcelona to Bangkok.** Retreat participants who had been involved in gender-based organizing at the International AIDS Conferences told their stories, and the outcomes of their work. The launch of both the International AIDS Society Women’s Caucus (IAWC) and the founding of the International Community of Women Living with HIV/AIDS (ICW) coincided at the 1992 International AIDS Conference in Amsterdam. Joyce Hunter and MariJo Vasquez reflected on these experiences (*note that although MariJo was not present for the founding, as an ICW Steering Committee member, she shared general impressions of that moment.*) Betsi

Pendry and Joyce Hunter discussed the work of Women at Durban; MariJo Vasquez, Nichanun Sodchuen, and Betsi Pendry recounted experiences from Women at Barcelona/Mujeres Adelante; and Monruedee Laphimon and Nichanun Sodchuen shared the inspirations of Barcelona, the challenges of Women at Bangkok, and the positive outcomes of work initiated in response to AIDS conference organizing. While organizing at conferences has its limitations, the value of conferences as a venue for bringing people together was clear. The very act of convening a space for advocates from different places and diverse backgrounds has a concrete positive ripple effect. Out of the experiences of both the Barcelona and Bangkok conferences, for example, local efforts were enhanced. In Barcelona, Creación Positiva strengthened its base and in Bangkok, the Thai Women and AIDS Task Force was born.

- b) **And today? What are we trying to build? What are we trying to do?** Reflecting on the history, and recognizing opportunities missed, we reviewed the recent conversations leading up to the retreat. As an entire group, and in smaller working groups, we began to articulate the core commitments and the operating principles of the effort we are building.

These conversations laid the groundwork for continuing dialogue in the days that followed. Ultimately, a draft mission statement and pronouncement of core operating principles was generated by the end of the retreat.

Highlights:

- Barcelona Bill of Rights as founding document
- Intersectionality and indivisibility of core issues – the network must always try to embody and advance this principle
- Independent voice – the need for a forum where contentious issues can be addressed
- Convening and coordinating – the need for a mechanism to bridge different sectors, and to coordinate effective communication and action
- Effective bridging of local and global – need for true relevance to grassroots actors
- Commitment to participation, diversity, and democratic governance

- c) **Who are we and what do we bring to the table?** During the afternoon, we catalogued the resources available in the room, and within easy reach of the network, due to affiliations and organizational resources. This asset mapping exercise was different than the morning introduction, which was designed for us to share our individual stories. In the afternoon exercise, we asked ourselves what we could bring to the network, such as skills, materials, knowledge, material resources, financial resources, clout, and professional affiliations.

Day Two –

- **Policy dialogue.** *Global policy Q&A: How do we advance an expanded response to women, girls, and HIV/AIDS? Discussion with Dr. Michael Merson, Yale University School of Medicine.* This was an informal dialogue session with Michael Merson, Director of the Center for Interdisciplinary Research on AIDS and former director of the WHO Global Programme on AIDS. A dynamic conversation took place, examining the role of the academic community in policy making. Other themes discussed included:

- While developing world governments must be more pro-active in implementing public health measures to address AIDS, funding conditionalities of the United States have had a significant negative impact on policy at the national level. The alarming effect is a roll-back in effective public health strategy – the Uganda condom debacle (in which over a million condoms were kept in a warehouse by the government) was a case in point.
 - International AIDS conferences are an important venue for community actors, academics, scientists, and policymakers to engage in dialogue. Unfortunately, the ‘dilution’ of the scientific emphasis at these conferences has diminished the appeal for academics and researchers. This shift has eliminated an important opportunity for necessary exchange. How do we ensure meaningful dialogue among the various actors that need to be talking to one another?
 - Those within the academic community hold prestigious positions – positions that have the imprimatur of neutrality – and they should be used to voice challenging positions.
- **Priority concerns and actions for the network.** Much of the second day was spent in small groups and in large group discussion, continuing to refine the priority concerns of the network, and to identify possible action steps. We looked at priority issues from both regional and thematic perspectives.

Actions this Network could take:

- Evidenced based advocacy
- Legal advocacy
- Make leaders of women in HIV/AIDS through voice
- Involvement of, including direct support for, grassroots actors
- Hold “town hall” style meetings on HIV/AIDS
- Communicate critical information to women
- Address cultural barriers to women’s rights
- See Toronto as a platform but build at community level in countries
- Translate information up and down
- Be a means of participation
- Leadership development through recognizing our own leadership and through bringing young women forward
- Link existing entities in related fields to HIV/AIDS
- Develop a vision and a sound bite - “make it sexy”
- Set the women and HIV/AIDS agenda
- Be a response mechanism, through press conferences and press releases
- Be a watch dog entity, vigilancia ciudadana

Premise and principles of the Network:

- Gender equity
- Cultural awareness
- Grassroots, indigenous participation (representation)
- Education
- Development of power and strategies
- Involvement of youth
- Actions are impact driven
- Shared leadership and distribution of power
- Effective, clear, and consistent communication
- Good documentation
- Non-hierarchical
- Diversity – geographic and gender identity and maintaining an active consciousness about diversity
- Inclusive of multiple voices, multiple cultures, and multiple vulnerabilities
- Commitment to democracy
- Internal accountability / Accountability through transparency and good governance
- Indivisibility and intersectionality of issues and identities
- Commitment to addressing neglected and contentious issues
- Independence
- Flexible and strategic
- Support ongoing efforts – don’t duplicate!
- Working with what s already in place – linking with and enhancing what is in place
- Governing bodies should “look like the epidemic”: mostly from developing world, black and Latina women from the North

Why this Network matters:

- Bringing women to the table – defining and promoting leadership
- Linking the global with the local in meaningful ways
- Translate every day realities into practice
- Bridging the women’s rights, sexual and reproductive rights, and HIV/AIDS communities
- Real prevention that addresses men, violence, reproductive health, gender equity
- Need more efforts to stop the pandemic among women
- Harness the momentum of the Barcelona Bill of Rights
- Intent to complement ICW
- Indivisibility of rights
- Prioritizing neglected, contentious issues
- Helping local groups do better advocacy
- Men to take leadership on gender, not just women

- **Network structure.** A working group deliberated and presented possible structures for the network to the larger group. The benefits and costs of establishing structure at this stage were also discussed. While some degree of structure is required to move activities forward, the risks of burdening a nascent entity with too much procedure was also raised. Rather than formalizing the structure at the retreat, the group decided to continue work through fall 2005 as a collective linked primarily through email and phone conferencing.

Day Three –

The final day was organized to allow time to finalize decisions, to continue working as a group, and to set a six month strategy.

- **Network name.** Potential names were developed and a voting process was administered via e-mail post-retreat. Finalists included the Barcelona Bill of Rights Network; AIDS, Gender, Rights, and Equity; and ATHENA. ATHENA was ultimately chosen, with the associated tag line of “Advancing gender equity and human rights in the global response to HIV/AIDS.” ATHENA was originally proposed because of her mythological representation as the Goddess of Wisdom and War, a fitting characterization of the network’s mission to raise awareness and mobilize diverse sectors.
- **Network values.**
 - Respect for internationally-recognized human rights
 - Commitment to achieving gender equity
 - Commitment to democracy that includes shared leadership and distribution of power
 - Commitment to geographic and gender diversity and maintaining an active consciousness about diversity that facilitates the inclusion of multiple voices, multiple cultures, and multiple vulnerabilities
 - Commitment to contribute actively to shared network activities
- **Governing principles.**
 - Indivisibility and intersectionality of issues and identities
 - Independence to address sensitive and contentious issues
 - Inclusion of grassroots and indigenous groups
 - Involvement of youth
 - Selection of actions based on their potential impact
 - Effective, clear, and consistent communication
 - Strong documentation and dissemination of network actions
 - Accountability through transparency, good governance, and inclusion

- Linking and enhancing work being done by Network members
- Acknowledging one another's work in joint projects and within the context of Network activities
- Expression of cultural awareness in documents and activities undertaken by the Network

Retreat outcomes

The most significant outcome of the retreat was a re-affirmation of the need for, and a collective commitment to creating, a network to bridge the diverse communities working to advance gender equity and human rights in the global response to HIV/AIDS. Having the structured time and space to engage in in-depth discussion enabled us to clarify a mission, and to strengthen a set of foundational relationships through which this mission will be achieved. An effort to build a truly global effort, across sectors and disciplines, is a true challenge. The value of this opportunity to meet face-to-face, and to address complicated questions, cannot be underestimated.

The retreat, including the preparatory process and immediate follow-up, yielded important tangible results. Through this process, we were able to:

- create ATHENA: a network to advance gender equity and human rights in the global fight against HIV/AIDS;
- develop an interim governance structure for this emerging initiative;
- draft a policy analysis/issue brief in the three focal areas of 1) human rights and ethics, 2) linking reproductive and sexual rights with HIV/AIDS, and 3) gender equity in treatment, care, and support;
- craft a research agenda for women, human rights, and HIV/AIDS issues;
- identify possible action steps for the network, including 1) a proposed campaign on the right to know and have for women and HIV/AIDS; and 2) the development of a gender equity gauge in the context of women and HIV/AIDS;
- establish an international working group to coordinate with the Blueprint for Women and HIV/AIDS in Canada in planning for activities leading up to and during the International AIDS Conference in Toronto, 2006.

Significant groundwork has therefore been laid and momentum established.

III. Policy Priorities: Acting on Rights

Women and girls have the right to:

To live with dignity and equality.

To bodily integrity.

To health and healthcare, including treatment.

To safety, security and freedom from fear of physical and sexual violence and abuse throughout their lives.

To be free from stigma, discrimination, blame and denial.

To their human rights regardless of sexual orientation.

To sexual autonomy and sexual pleasure.

To equity in their families and intimate partnerships.

To education and information.

To economic independence.

-Excerpted from the Barcelona Bill of Rights, 2002

Women, Girls, and HIV/AIDS: A Policy Failure

If the carnage of this pandemic has taught us anything, it's the terrifying vulnerability of women. I feel I must say that the greatest single international failure in the response to HIV/AIDS, is the failure to intervene, dramatically, on behalf of women.¹

-Stephen Lewis, Statement from the opening of the International AIDS Society Conference, July 24, 2005

In Africa, AIDS has a woman's face.

-Kofi Annan, The New York Times, December 29, 2002²

In the more than twenty years of the HIV/AIDS pandemic, the global community and the global response to HIV/AIDS have failed women and girls. Women account for nearly half of the 40 million people living with HIV around the world. Even as this number is growing and the number of young women infected with HIV/AIDS is rapidly outpacing that of young men in Southern Africa, for example, we have policies that hinder the ability of the global community to respond effectively, efficiently, and equitably to women and girls living with and at risk of HIV/AIDS. To date, we have seen little, if any, success in slowing or halting the spread of HIV/AIDS among women and girls in any region of the world.

Here are three currently significant challenges we discussed that represent the failure for women and girls of global HIV/AIDS policy:

¹ Available at <http://www.stephenlewisfoundation.org/articles/2005-07-24-ias-rio.html> accessed on September 30, 2005

² Available at <http://www.un.org/News/ossg/sg/stories/articleFull.asp?TID=15&Type=Article> accessed on September 30, 2005.

- 1) **ABC** – Community leaders in Uganda assert that there is a dramatic shortfall in condom supplies and that the Ugandan government has purposefully limited the condom supply because of international pressure, specifically that from the United States. More broadly, abstinence only education has elbowed out evidence based comprehensive sexuality education in Uganda and other neighboring countries where marriage is the greatest HIV risk factor for many young women. On a global front, the shift away from robust sexuality education and comprehensive prevention is similarly undermining efforts to halt the pandemic.
- 2) **Anti-prostitution clause** – DKT International and the Alliance for Open Society International and the Open Society Institute have brought respective lawsuits against the United States government challenging the United States Agency for International Development’s Acquisition and Assistance Policy Directive of June 9, 2005. This directive is to “prohibit the funds provided under the agreement to be used to promote the legalization or practice of prostitution or sex trafficking; and require recipients to agree that they oppose prostitution and sex trafficking.”³ DKT and AOSI/OSI contend that “this policy is an unconstitutional infringement of speech that is also undermining international efforts to stem the scourge of HIV/AIDS.”⁴
- 3) **Ban on needle exchange** – Injecting drug use is a central factor in the disproportionately high rates of HIV infection among African-American and Hispanic women in the United States. It has also led to a 50% increase in infections among women in Asia and Eastern Europe over the past 2 years.⁵ The U.S., however, continues to restrict funding for and support of needle exchange programs.

While these three policies all emanate from and are driven by the United States, they constitute substantial barriers to developing policies and implementing programs that adequately address HIV/AIDS issues affecting women in other countries due to the reliance of the global community upon funding restricted by these conditionalities. These three policies stand as only the “tip of the iceberg” introduction to the failure of the global community to adequately address women and HIV/AIDS.

Furthermore, while the global community has been passionately calling for policies, programs, and research that move beyond the biomedical model for over a decade, little has changed. In 1993, Paul Farmer and his colleagues asserted “by the mid-1990s, global human immunodeficiency virus (HIV) infections among women are expected to equal those among men. This trend reflects economic, political, and cultural factors that limit women’s ability to protect themselves from HIV transmission.”⁶ And in 2005, Thomas Quinn asserts that “this growing ‘feminization’ of the HIV-1 pandemic reflects women’s greater social and biological vulnerability.”⁷ Yet our understanding of and response to the structural factors at play in women’s vulnerability to HIV/AIDS and the robust societal role of gender inequity in disease

³ Available at http://www.usaid.gov/business/business_opportunities/cib/pdf/aapd05_04.pdf accessed on October 3, 2005.

⁴ DKT statement August 12, 2005, received by email.

⁵ UNAIDS, UNFPA, UNIFEM, *Women and HIV/AIDS: Confronting the Crisis* (UNAIDS, New York, 2004) available at <http://www.unfpa.org/hiv/women/report/index.htm>.

⁶ Farmer P, Lindenbaum S, Good MJ, “Women, poverty and AIDS: an introduction.” *Cult Med Psychiatry*. 1993 Dec;17(4):387-97

⁷ Quinn, T, Overbaugh, J, “HIV/AIDS in Women: An Expanding Epidemic.” *Science*. 2005 June 10; 308: 1582-1583.

transmission and progression remain limited, confined largely to case studies, documentation efforts, and small-scale interventions. Partnership across sectors, fields, and regions is needed so that we continue to address the structural causes of women's vulnerability; to better understanding how gender inequity operates; and to determining the role of rights in this dilemma.

A SNAPSHOT OF NEGLECTED POLICY ISSUES AND PRIORITIES BY REGION

From a global and/or local perspective:

- Abstinence only policies and the need for comprehensive sexuality education
- Invisibility of women drug users and female sexual partners of drug users in harm reduction research and interventions
- Development of evidence based prevention messages that make sense to and are feasible for women and girls
- Development of policies to address reproductive choice for persons living with HIV/AIDS
- Implementation of efforts to expand HIV testing such as provider initiated opt-out HIV testing versus voluntary counseling and testing
- Gender equity in treatment access

Southeast Asia/Thailand:

- Rights to decide whether and when to have children (including safe pregnancy and abortion)
- Sexuality education for all women, not just adolescents
- Availability and accessibility of an array of prevention options including condoms, female condoms, and microbicides
- Standardized services for pregnant women living with HIV/AIDS
- Promoting women's full knowledge of risks and benefits of nevirapine administration as a method to prevent perinatal HIV transmission
- Invisibility of women drug users and the violence they face

Latin America/Bolivia:

- Broadening the focus of programs from men who have sex with men and commercial sex workers to the general population
- Expanding the focus of prevention so that it is culturally appropriate (currently, condom-based and using middle-class Westernized messages)
- Inclusion of economic issues in prevention, care, and treatment programs for women
- Increasing attention to issues of domestic and sexual violence in the context of HIV/AIDS

Africa/Uganda:

- Increasing attention to issues of gender-based, domestic, and sexual violence in the context of HIV/AIDS, including marital rape and child sexual abuse
- Condom use as a sound and available method of prevention
- Increasing attention through research, law, and policy to harmful traditional practices, including female genital cutting, dry sex, bride price, polygamy, widow inheritance, "cleansing" through sex with virgins
- Preserving parental rights of people living with HIV/AIDS (child custody, adoption)
- Prevention and care programs in conflict areas (refugees, internally displaced persons)

North America/ New York City:

- Relationship of gender-based violence to substance use and mental health
- Basic needs of women living with HIV/AIDS such as housing, primary care, and reproductive and sexual health services

IV. Advocacy Challenges: Bridging Communities and Movements

Lessons learned from bringing diverse stakeholders to the table:

What are the challenges and what are the opportunities? Why do these collaborations not exist? How do we resolve these divides or this lack of coordinated action?

Feminists and HIV/AIDS

One of the striking issues that is raised time and again – whether it be in India, South Africa, or during the retreat – is the stark absence of the feminist community in responding to HIV/AIDS. Individual feminists have responded to HIV/AIDS and many of the most pioneering feminists today are women living with HIV/AIDS. However, the women’s rights movement has not, by and large, taken on HIV/AIDS as a central concern. This absence is all the more remarkable as issues of economic rights, sexuality, and equity are all at the core of the HIV/AIDS pandemic.

A colleague from Bolivia, a young woman living with HIV/AIDS and an anthropologist, noted with dismay the response of Latin American feminist scholars broadly to HIV/AIDS and the response of the women’s rights community. Her experience has been that both communities have intentionally shunned or ignored the problem of HIV/AIDS. Instead, this young woman found support from and alliances with the gay male community.

In India, as recently as three years ago, women’s rights groups and reproductive and sexual health groups actively ignored HIV/AIDS due to its stigmatizing nature. This is beginning to shift somewhat – but not very far. Networks of positive women and sex worker groups have been the notable exception.

The response in South Africa has been similarly surprising. HIV/AIDS is not a central issue on the agenda of women’s rights groups nor is it consistently a part of human rights work in that country. This is not to say that there is not considerable effort underway to address HIV/AIDS from a women’s rights perspective – only to remark that entities that are not first and foremost responding to HIV/AIDS lack the consistent recognition of the links between these different issues and communities.

Challenge: How do we build better bridges from HIV/AIDS to the feminist and women’s rights communities to foster and advance these important alliances?

Reproductive Health and HIV/AIDS

The reproductive health community has only recently begun to address HIV/AIDS on a global and regional scale. Similarly, the HIV/AIDS community does not consistently consider the sexual and reproductive health implications of HIV. There has been a failure to apply the decades of knowledge and experience in advocating for change and providing reproductive health services to HIV/AIDS that is slowly changing. The recent reviews of the 1995 Fourth World Conference on Women’s Beijing Declaration and Platform for Action and the 1994 Cairo International Conference on Population and Development’s Programme of Action both had HIV/AIDS as their focal issues. It is interesting to note that the actors involved in both of these

reviews were those who have been involved since those conferences occurred a decade ago and did not, to a significant extent, include entities that have HIV/AIDS as a core mandate. Individuals entering HIV/AIDS from a women's health background query why there has not been a larger shift in the women's health community and why it is only now that some of these bridges are beginning to be built. This is especially critical considering the shift away from comprehensive sexuality education and reproductive choice toward abstinence only messages and continued restrictions on abortion for US funded entities.

Opportunity: How do we build upon the new momentum within the reproductive health community to expand collaborative efforts and the scope of our inquiry?

Harm Reduction and HIV/AIDS

The harm reduction community has been a stalwart figure in the response to HIV/AIDS – and has been a key entry point for HIV work in many parts of the world. The challenge is the absence of a consistent gender perspective. HIV/AIDS advocates from the United States and Thailand both discussed how the harm reduction movement has been largely dominated by men with insufficient attention paid to women drug users, the female sexual partners of drug users, and the relationship between drug use and violence. Thai colleagues in particular noted the absence of women and women's issues in the Thai Drug User Network.

Harm reduction broadly is under serious assault whether it be needle exchange, condom distribution, or work with specific populations. The implications of the US government anti-prostitution pledge, diminishing support for condoms or comprehensive sexuality education, and stance against needle exchange are significant for regions where epidemics are well established such as across Africa and for regions with relatively young and aggressive epidemics such as Eastern Europe or China.

Challenge: How do we integrate a more gendered perspective and lend our support to this community?

HIV/AIDS Treatment and Care Providers

HIV/AIDS treatment and care for women remains largely tied to the perinatal setting. Many large anti-retroviral rollout programs do not disaggregate data by age or sex. Those programs that do target women typically only do so through the limited context of preventing HIV transmission to infants. In addition, many of the treatment access movements have to date been led by men with a lack of attention to gender as well.

The retreat participants noted that when they are invited to attend high-level meetings on treatment and care they are typically the sole woman in the room and one of the few individuals living with HIV/AIDS. A gender perspective is not present in these discussions and their attempt to introduce such a perspective is muted.

Very little is understood about access to antiretroviral care for women and girls. Inferences can be drawn from parallel scenarios and small-scale reviews that have been done, such as those undertaken by ICW to identify barriers to care. There is significant concern that violence and fear of violence are important issues to consider that have not, to date, been so.

Another central challenge is the lack of treatment literacy and preparedness for women and girls. A colleague from Bolivia discussed how many women she knows stopped treatment

when they suffered severe side effects due to inadequate information on how to take their medication, such as with food or between meals. She remarked that the physicians do not have this knowledge – and if they do, do not share it with their patients. When asked how men find out these things, she observed that this essential knowledge is shared with positive person networks dominated by men in her country. A Thai colleague commented that inadequate information is provided to women about the potential hazards of single therapy nevirapine used to prevent transmission of HIV during pregnancy. A Ugandan colleague noted the lack of materials on gender and treatment access or on women and antiretroviral therapy in her country, which is striking considering the global attention Uganda has received both for its success in managing its HIV/AIDS challenge, as well as for its progressive inclusion of women’s issues on the national political front. The Ugandan colleague is a medical doctor and will be an active member of the evaluation committee for WHO’s 3x5 program – providing an opportunity to highlight these inconsistencies in an international forum.

Opportunity: With the global scale-up of antiretroviral therapy, what are the steps we can take now to ensure better gender equity and the availability of treatment for all women who require it?

LGBTQ/I Community and HIV/AIDS

In many parts of the world, the LGBT community has been an important entry point for HIV/AIDS related advocacy, awareness, and support. The LGBT groups in India, for example, have been a strong front of coordinated action and a strong voice. As a colleague noted in Bolivia, the LGBT community – specifically the gay male community – has been the main ally for women living with HIV/AIDS. And many leaders in HIV/AIDS have come from the gay rights movement.

It is interesting to note that there has been a bi-directional relationship between HIV/AIDS and LGBTQ/I issues in many regions of the world. The LGBT community has been quick to respond to HIV and in the same vein, the way in which HIV has put sexuality into public discourse has strengthened the LGBT community. A colleague from India noted a few years ago how the gay community in Mumbai has become more visible with the rise of HIV/AIDS.

Opportunity: How do we better integrate consideration of sexuality and orientation in our own work and continue to foster these bridges?

Sex Work Community and HIV/AIDS

The sex work community has been a lead respondent to HIV/AIDS and has proven, in many ways, to be the most innovative. Protection from transmission has been understood more broadly than conventional prevention messages as being intimately linked to the rights of women. Messages have been those of empowerment and control not fear, blame, and stigmatization. However, the increasing pressure from the US government for entities receiving any US monies to sign anti-prostitution pledges will likely have a significant impact on the progress made by the sex work community to prevent transmission.

While the sex work community has been a strong voice and actor in HIV/AIDS, sex workers living with HIV/AIDS are typically absent from treatment and care settings due to discrimination by health care workers. In addition, individuals who exchange sex for goods informally are not often reached by the sex work community for prevention interventions or support mechanisms.

The LGBT community has been a more regular ally of the sex work community. The reproductive health community, HIV treatment providers, and feminists have been absent or inconsistent in working with this community.

Challenge: How do we forge alliances with this community and address the full range of issues women living with or at risk of HIV/AIDS face?

Implications for Sexual Health and Rights, Marginal Communities, and HIV/AIDS

The double stigmatization of HIV/AIDS and of marginal communities makes bringing various actors together challenging. Skepticism and mistrust are inevitable when working across backgrounds and regions. Furthermore, fragmentation around issues such as sexual orientation, reproductive choice, and harm reduction occurs.

This being said, it is a critical moment for independent and integral actors to highlight and address sexual and reproductive health and rights, marginal communities, and HIV/AIDS as the progress that was gained over the past decade or so is rapidly being undermined. Comprehensive sexuality education is missing. Condoms are being left in storehouses. Prevention messages that don't work are pushing out evidence based efforts. Treatment and care is going toward women as mothers – and not women broadly. The issue of unsafe and coerced abortions among women living with HIV/AIDS is ignored. Work with marginalized groups is becoming impossible for entities reliant upon or at all tied to United States' government funds.

Strategies for Change

- **Keep the issues on the table** – Support to amplify the voices and advance the work of those who will continue to address contentious and overlooked concerns is needed.
- **Forums to bridge communities** - There is insufficient communication and partnership between overlapping communities. Continued forums to bring these communities in dialogue and to foster new alliances are needed.
- **Collaborative efforts** - Funding for collaborative initiatives is a key way for these partnerships and alliances to grow.
- **Mechanisms to sustain collaboration** – Sustained mechanisms such as networks or other bridging structures are needed once key alliances and partnerships are formed.
- **Translating the global to the local, local to the global** – Mechanisms are needed to ensure that global debates are informed by local experience and that local experience is strengthened by global action. This means involving local actors in global debates and making global debates accountable to local actors. Bringing new voices to debates is one means of achieving this goal as is fostering the leadership of pioneering community based leaders.
- **Support for local initiatives** – Small grants to local actors (both individuals and organizations) to allow for innovative, bridging work to occur is a very direct and very simple means of linking these communities.
- **Bottom line** – Bring diverse actors to the table, provide them financial support to undertake cross-cutting work, and then develop and sustain structures to strengthen those alliances.

V. Research Imperatives: Setting an Expanded Research Agenda for Women, Girls, Human Rights, and HIV/AIDS

Key research themes and challenges:

The practice and politics of international research on women, girls, and HIV/AIDS

1. How do we pursue research in ways meaningful to women and girls living with and affected by HIV/AIDS?
 - a. Building community partnerships
 - b. Involvement of women and girls in research design, implementation, and analysis
 - c. Providing feedback to research participants
 - d. Translating our research findings into interventions to address everyday realities
 - e. Examining and understanding the total experience of women, for example that we can't divorce research on microbicides from the ethics of clinical trials or the reality of domestic and sexual violence
2. Challenges of building bridges between research, policy, and practice
 - a. How can researchers be advocates?
 - b. How can research be a means of social change?
3. Challenges of bringing various stakeholders to the table
 - a. What are the benefits of interdisciplinary research?
 - b. What are the benefits of participatory research?
4. Current challenges of pursuing research and developing sound policies/programs
 - a. Implications of funding conditionalities and political climate
 - i. Global gag rule on abortion and daily reality of forced abortions, sterilization for women living with HIV/AIDS
 - ii. Anti-prostitution clause and ability to address marginalized communities or survival/transactional sex
 - iii. ABC and juxtaposition of marriage as a risk factor for HIV
 - iv. Needle exchange ban and efforts to erode support for needle exchange globally when injecting drug use and being a sexual partner of an injecting drug user is driving the epidemic in multiple regions of the world

Feminization of the pandemic: Perspectives and priorities of women living with HIV/AIDS

1. How will the practice of research and research findings affect daily realities?
 - a. Will research be a means of social change?
 - b. Will research extend lives and advance health?
2. Lack of a robust gender perspective in a range of research endeavors addressing HIV/AIDS from clinical trials to social science research
3. Challenges of addressing and advancing contentious or neglected human rights concerns through research and policy

4. Challenges of addressing the indivisibility of rights and the intersectionality of issues
5. The role of law and policy in addressing HIV/AIDS from a women's rights perspective

Research priorities that need to be addressed/have been relatively neglected

1. Gender equity in access to care, treatment, and support
 - a. Making women and girls count – disaggregating data by sex and age
 - b. Antiretroviral treatment access beyond the perinatal setting, i.e., ART as therapy for women, not just as prophylaxis to prevent perinatal HIV transmission
 - c. Understanding the role of violence in access to and continuation of therapy
 - d. Understanding the obstacles and barriers to care: pragmatic, such as clinic hours or pill burden; cultural, such as norms and practices; ideological, such as opposition to reproductive choice, expression of sexual orientation other than heterosexuality, etc.
 - e. Treatment literacy
 - f. Participation of women in clinical trials
 - g. Side effects of treatment for women
2. Linking reproductive and sexual rights and health with HIV/AIDS
 - a. Reproductive choice
 - i. Right to have children, including right to pregnancy and assisted reproduction for both women and men
 - ii. How best to involve men
 - iii. Right to safe induced abortion and care for treating complications of miscarriages and unsafe abortions
 - b. The use of the HIV/AIDS pandemic to promote abstinence only education and limit women's access to reproductive health information and contraceptives
 - c. Comprehensive sexuality education for all women and girls, irrespective of age
 - d. Is HIV testing in the perinatal setting increasing access to services and treatment or is it a barrier to prenatal care?
 - e. HIV prevention methods that
 - i. Permit conception
 - ii. Work for women living with HIV/AIDS
 - f. Incidence and prevalence of forced/coerced abortion and sterilization for women living with HIV/AIDS
 - g. Relationship of sexual violence
 - i. Access to PEP
 - ii. Access to emergency contraception
 - h. Denial of services to women living with HIV/AIDS/restrictions on services
 - i. Making ART contingent on using certain contraceptive methods
 - ii. Denial of gynecologic/obstetric care for these women
 - iii. Access to reproductive health care other than antenatal care: screening for and treatment of gynecological cancers (including use of simple, inexpensive technologies), emergency contraception, postabortion care, safe induced abortion, postpartum care, menstrual disorders
 - i. Medical providers' denial of sexual and reproductive rights and care to women who partner with women.
 - j. The effect of antiretroviral therapy on reproductive health throughout the life cycle: pubertal development, fertility, pregnancy, peri-menopausal period

3. Identifying research priorities for advancing a human rights based response to HIV/AIDS
 - a. Access to technology and scientific advancement
 - i. Including all HIV prevention methods condoms, female microbicides, female condoms
 - b. HIV testing
 - i. Implications of provider-initiated testing for
 1. Informed consent
 2. Confidentiality
 3. Access to health services
 4. Stigma and discrimination
 - ii. How best to expand voluntary testing and counseling so that women are reached outside the setting of pregnancy
 - iii. Reaching more men
 1. Factors that can contribute to increased couple/partner voluntary testing and counseling
 - c. The relationship between HIV/AIDS, gender, and violence and how the contributory factors can be addressed
 - i. Domestic violence
 - ii. Sexual violence
 - d. Social disruption
 - i. Prevention and care in conflict areas
 - e. Implications of harmful traditional practices
 - i. Female genital cutting
 - ii. Dry sex
 - iii. Bride price
 - iv. Polygamy
 - v. Virgin and widow cleansing
 - f. Role of law and legal rights
 - i. Child custody and legal adoption by people living with HIV
 - ii. Property rights
 - iii. Inheritance rights
 - iv. Age of legal marriage
 - v. Marital rights
 - vi. Divorce
 - vii. Violence
 - g. Right to education and information, including specific information about protecting oneself from HIV infection and about treatment for HIV/AIDS (treatment literacy)
 - h. Economic survival and viability of women living with and vulnerable to HIV/AIDS

VI. Innovative Alliances: Launching ATHENA

ATHENA: ADVANCING GENDER EQUITY AND HUMAN RIGHTS IN THE GLOBAL RESPONSE TO HIV/AIDS

Mission, values, and guiding principles

As the world enters the third decade of the global HIV/AIDS pandemic, women - especially the young and the poor - are increasingly affected. Because gender inequity fuels HIV/AIDS and HIV/AIDS fuels gender inequity, it is imperative that women and girls speak out, set priorities for action, and lead the global response to the crisis.

ATHENA was created to realize this imperative. The Network builds upon the work of individuals and entities who have been committed to this challenge for years, and intends to use coordinated, collective action to advance their efforts further. ATHENA members are working actively towards the realization of the *Barcelona Bill of Rights*, a guiding document for the Network that was first promulgated at the 2002 International AIDS Conference.

Network mission

The Network's mission is to:

- Advance the recognition, protection, and fulfillment of women's and girls' human rights, comprehensively and inclusively, as a fundamental component of policies and programs to address HIV/AIDS.
- Improve the life quality and longevity of women and girls living with HIV/AIDS.
- Ensure gender equity in HIV/AIDS-related research, prevention, diagnosis, treatment, care, and support.
- Promote and facilitate the leadership of women and girls, especially those living with HIV/AIDS, in all aspects of HIV/AIDS-related policies, programs, and research.
- Bridge the communities around the world that are addressing gender, human rights, sexual and reproductive health, and HIV/AIDS.

In advancing this mission, we aim to:

- Address neglected or contentious human rights issues such as sexual and reproductive rights.
- Link the global with the local in meaningful ways, for example, by linking and facilitating dialogue between actors operating in different regions, sectors, and realms.
- Link research, policy, advocacy, and practice.
- Share information and experiences.
- Develop common agendas for joint advocacy, shared research, and collaborative training programs.
- Develop and support the leadership capacity of women and girls, especially those living with HIV/AIDS.
- Enable individuals and organizations to be agents of change, including through provision of support to activists and advocates for women and girls living with and at-risk for HIV/AIDS.

Network values

Values on which the Network's actions and activities will be based include:

- Respect for internationally-recognized human rights
- Commitment to achieving gender equity
- Commitment to democracy that includes shared leadership and distribution of power
- Commitment to geographic and gender diversity and maintaining an active consciousness about diversity that facilitates the inclusion of multiple voices, multiple cultures, and multiple vulnerabilities

Guiding principles for Network actions and activities

In striving to achieve our mission and express the values we have endorsed above, our work will be guided by the following principles:

- Indivisibility and intersectionality of issues and identities
- Independence to address sensitive and contentious issues
- Inclusion of grassroots and indigenous groups
- Involvement of youth and the importance of intergenerational dialogue
- Selection of actions based on their potential impact
- Effective, clear, and consistent communication
- Strong documentation and dissemination of Network actions
- Accountability through transparency, good governance, and inclusion
- Commitment to contribute actively to shared Network activities
- Linking and enhancing work being done by Network members
- Acknowledging one another's work in joint projects and within the context of Network activities
- Expression of cultural awareness in documents and activities undertaken by the Network

Appendix I

Meeting Minutes

Wednesday, July 6, 2005

History of the movement

Amsterdam Conference, 1992

- Creation of the Women's Caucus of the International AIDS Society to make women's issues visible
- Creation of the International Community of Women Living with HIV/AIDS (ICW)
 - 40 women from 27 countries
 - Only network run by and for women living with HIV/AIDS

Achievement: Launch of ICW and the Women's Caucus of the International AIDS Society

Yokohama Conference, 1994

- Focus on women
 - First and last conference to have a gender focus
- Question: What created it? Why hasn't it been sustained or replicated?

Durban Conference, 2000

- First international AIDS conference in the developing world AND in a largely affected country
- Wanted a parallel conference to collaborate with partners, albeit acting independently, to allow regular South African women access to Conference resources and a platform
- Acknowledgement of lack of information being shared with local population, as well as the need to bridge the gap between global and local
 - Important way to bring most recent science to women and to bring the experience to actual participants in the conference intended to maximize opportunity for dialogue and interaction between higher-ups and average citizens
- Emerged from conference with grand plans, but had no way to achieve these plans

Lesson learned: Importance of creating sustained structures to capture energy and momentum of these gatherings

Achievement: Robust participation of local women

Barcelona Conference, 2002

- Spanish women wanted to reproduce Durban conference because they felt frequently excluded from international conferences due to language
- Implemented another parallel conference to not only highlight gender issues but also create a tool to enable the movement to move forward
- Global collaborative effort to create Barcelona Bill of Rights
 - Barcelona Bill of Rights showed that it is possible for a global effort to be participatory and effective
 - Inclusion of reproductive choice, specifically safe abortion, in the in Bill of Rights has made it impossible for various entities to endorse and support
- Mujeres Adelante continues: Local women remember the Barcelona meeting, feel proud, feel ownership, and a sense of belonging

Question: How do we facilitate the full participation of women living with HIV/AIDS in the global forums to address HIV/AIDS?

Achievement: Strengthening of local efforts through global presence and the creation of the Barcelona Bill of Rights

Bangkok Conference, 2004

- Canadian satellite session by CIDA and Health Canada on Barcelona Bill of Rights
- In contrast, women's leadership track did not explicitly recognize or reference the Barcelona Bill of Rights
- Recognition of language barriers present at such conferences
- Enjoyed working with women's groups outside of solely HIV issues, built networks between groups in preparation for Bangkok AIDS Conference with the creation of the Thai Women and HIV/AIDS Task Force
- Pre-conference focused on how to build capacity with limited resources
- Intent to raise awareness of Thai women related issues within the context of global
- Women came with identities related to organizations as well as personal identities, chance for women involved with AIDS to work specifically on gender-related issues
- Solution at Bangkok Conference: people gathered for smaller meetings to discuss gender
- Have since established a successful and sustained national Thai network

Challenge: Gender issues not being addressed in context of AIDS

Achievement: Creation of strong national Thai network to address women and HIV/AIDS

Toward Toronto, 2006

- Strong push to have women's concerns better represented than at Bangkok
 - Belief that women (particularly young women) were underserved and underrepresented at Bangkok, this should be addressed in Toronto
- Canadian government support for the Barcelona Bill of Rights, as evidenced by satellite session in Bangkok
- Collaboration with the Blueprint for Action

Small groups: Goals for retreat

1. Develop a network to create/support women's social movements that have a sustainable impact
2. Central importance of incorporating and empowering women living with HIV/AIDS and grassroots women, and not becoming an elite entity that focuses solely on conferences
3. Discuss the role of legal advocacy
4. Develop a plan for leadership development (for purposes of sustainability)
5. Develop a vision + soundbyte for presenting the network publicly
6. Identify: Who is the target audience? Where are the leverage points? Is the UN one of them?
[Note - by the end of the retreat, the consensus was NO] Who are potential allies?
7. Ensure that we do not lose sight of how issues intersect
8. Plan for visibility and plenary time at Toronto
9. Create a platform for raising issues independently

Getting concrete

What exactly is being created? (The "It")

- A committed entity with structure and resources that will sustain itself

How to create it?

- Need "glue" to link everyone in a sustainable way while still allowing for flexibility

- Identify women's unmet needs: What are the needs? Where are the gaps? Who is meeting the needs and gaps already?
 - Identify, prioritize, act
- Figure out how to bring together academic feminists and others together for work and advocacy while taking care not to alienate women living with HIV/AIDS in the process

What will it DO?

- Promote idea that work done by individual outside networks should help build the greater community of people involved in these issues
- Promote "intersectionality" (interaction and participation in the movement that involves different sections of society—race, class, etc.)
- Advance a feminist perspective not just through women
- Represent and address women's unmet needs

Individual thoughts and concerns

- "I think the role of women who have power is to empower those who do not have power."
- "Women don't groom each other for positions of power and leadership the way that men do—this network should address that unmet need."
- "This network should NOT be hierarchical."
- "Who is a feminist? This is something we should discuss and qualify."
- "We should explore issues of identity, particularly identity as it relates to being HIV+."

Afternoon group discussions

Core principles:

- Gender equity
- Cultural awareness
- Grassroots participation/representation with direct support for grass roots entities
- Accountability/transparency and governance

Operating principles:

- Actions are impact driven
- Effective communication
- Shared leadership
- Non-hierarchical
- Representation and participation of grassroots
- Incorporation of and active consciousness concerning diversity—sexuality, geography, HIV status
- Democratic decision-making
- Internal accountability
- Indivisibility/intersectionality of core issues and identities
- Community organizing and mobilization
- Improving the lives of women and preventing infection

Actions:

- Gather/exchange information
- Foster dialogues
- Foster leadership development
- Secure funding to be self-sustaining
- Hone language/guidelines on comprehensive HIV prevention
- Develop into a watchdog group

- Speak with an independent voice
- Create a training institute for human rights advocacy around gender and HIV/AIDS
- Redefine “advocacy” and re-own the term

Working groups discussions on commitments, principles, and actions

~ Group One

- Commitments to: gender equity, cultural awareness, grassroots/indigenous participation and representation, education and the development of power strategies, accountability, transparency, and governance
- Operating principles: action and impact driven, shared leadership, effective communication, non-hierarchical, representation of grassroots, maintaining an active consciousness of diversity, commitment to internal democracy, internal accountability, indivisibility and intersectionality of issues and identities
- Actions: general actions vs. specific; both must be identified

~ Group Two

- Commitments to: add ‘violence’ to sexual and reproductive health; supporting the people who support the issues (women’s rights, women’s leadership); substitute ‘meaningful mutual support’ for ‘linking’, grassroots mobilization = a gap
- Operating: bridge sexuality, gender, and human rights; share information and experiences; design and implement joint campaigns, inform and direct global communication;
- Actions: act a watchdog that can agitate for change from other groups, training institute for human rights advocacy, community organizing and organization

~ Group Three

- Commitments/principles: issues others are afraid of taking on (rep. choice, harm reduction, comprehensive sex ed.); independence; grassroots involvement
- Why and what for?
 - Gender equity, information sharing, clearinghouse, flexible and strategic, identify and fill gaps, networking, HIV/AIDS may be the glue, watchdog, global-national, identifying contested issues
- Advocacy: redefining, to governments, and to agencies

Thursday, July 7, 2005

Global HIV/AIDS policy Q&A with Michael Merson

- The pressing question in the global response to HIV/AIDS is will women get care.
- WHO’s 3x5 program has driven an increased response to the pandemic and has dramatically increased the amount of available treatment.
- With the increasing dedication of resources to treatment, there is a question of how much money will remain for prevention.

- A critical issue that is gaining consensus is that we must stop treating women just for their babies. PMTCT only is not the right way.
- Any entity receiving US money for HIV/AIDS is now under Pefar.
- Pefar's genesis is political.
- While Clinton has now robustly embraced HIV/AIDS, he was late to the challenge as president beginning to respond only in 1998.
- Abstinence is a dangerous policy to women that is driven by the US Congress.
- Country responses such as that by Brazil is the answer as there is no current solution in DC.
- What is the role for the academic community?
 - To defend evidence based policy.
 - Where is the entry point?
 - Advocates should put forward these entry points.
- Where is the media?
 - 80% of the stories on HIV/AIDS come from the International AIDS Conferences

Key points:

- *Major issue is that change needs to take place at the country level, but it is hard for these governments to stand up to the US government or to be independent of US funding.
- *International AIDS conferences no longer draw the majority of the academic community, many do attend the scientific conferences.
- *A media strategy is essential.

Evaluating where we stand

Rachel: Wants to see something come out of this retreat that everyone feels excited about and connected to. Hopes group can find a core passion and move forward with specific activities that reflect that.

Monica: Important to determine what is being conveyed to university students through public health education and politics that are infiltrating the student body. Finding a regulated rhetoric for the media.

Pat: "People talk a lot. People don't listen." Sexual and reproductive health is essential in prevention.

Rung: Concerned that people are not listening enough within the network.

Violeta: Doesn't want this to be a network that pretends to work on women and AIDS issues but doesn't do anything. In some past cases of AIDS advocacy/activism, women with HIV have been incorporated into larger networks/organizations, but they were not involved in all levels of decision; that should not happen with this network.

Marjorie: Promote effective communication that is inclusive of the voices of women with HIV.

Lydia: Wants to work out ways to effect change and policy within national governments.

Janet: Wants to know that there will be a concrete impact on the most hard to reach women.

Reshma: “Strategized passion”—product, promotion, price, placement.

Julia: Need to channel anger and passion into political campaigns.

Ida: Wants to plan a task that will bring us together as a network.

Joyce: The group needs to work together.

Tyler: Wants all to leave the room with trust, respect for, and understanding of one another to form a strong building block.

Priya: “We cannot empower anyone until we empower ourselves.” –We need to set the global agenda, and do this by focusing anger on those who create policy.

Maria: Definitive wording for a mission statement and statement from each whether that statement would empower each person to obtain commitment from their organization to support the network.

Gregg: Concrete policy goals so can look back and see that this network made an actual difference. Need to promote capacity of positive women.

Luisa: How can we mobilize and react to violations of women’s rights?

MariJo: Develop a structure that creates a network with multiple channels for energy and activism.

Beri: Wants network to have influence improving quality of life in people with HIV, preventing new infection, and educating the masses around the world to prevent new infection.

Betsi: Mike Merson equated activism in the 90s with many people dying, but there are more people dying now. We need to take action.

Tricia: Wants this network to create optimism among younger generation entering the field.

Working session

Neglected or contentious issues / Priority concerns

A global – local perspective:

- Abstinence
- Reproductive choice
- Adolescent sexuality education
- Disclosure
- Opt-out testing
- Alienation of marginalized populations

- Harm reduction
- Prevention messages that make sense to women
- Gender equity in treatment access
- Women in injecting drug use communities

Southeast Asia/Thailand:

- Rights to pregnancy and abortion
- Sexuality education for all women, not just adolescents
- An array of prevention options including condoms, female condoms, and microbicides
- Standardized services for pregnant women living with HIV/AIDS
- Full knowledge of risks and benefits of nevirapine
- Invisibility of women drug users and the violence they face

Latin America/Bolivia:

- AIDS is not a priority
- Focus only on MSM and CSW with the rest of the population ignored
- Prevention is condom based, middle class western messages only
- Economic viability and survival of women, economic power
- No sexual autonomy of women, “Virgin Mary” culture
- Need for culturally sound approaches, rights are for educated women
- No generalized, appropriate prevention messages even while all women are vulnerable
- Violence

Africa/Uganda:

- Domestic violence
- Condoms
- Harmful traditional practices
- Genital mutilation
- Child custody
- Gender based violence/ Sexual violence
- Marital rape
- Conflict areas, abduction

Group discussion on interim structure

Structure

Short term → Interim spokesperson (not excluding others)

- Elected by nomination or ballot
- Follow up on identified items
- Continue work of permanent structure
- Coordinate
- Pursue funding

Long term

- Membership
 - Allow all who endorse goals and principles of coalition or Barcelona Bill of Rights
 - North-South representation
 - Importance of grassroots participation
- Regional representatives pick regional spokesperson
 - Promote regional community

- Decision making and coordination
- Work groups (3 alternatives)
 - Funding; education and outreach; advocacy and policy
 - Human rights and ethics; sexual and reproductive rights; gender equity in treatment access
 - Community building and coordination; campaign and advocacy; education and training
 - Discussion: Should these be thematic, issue oriented working groups or task oriented working groups?
- Steering Committee
 - 8 regional spokespersons from regions
 - Will select secretariat (chair) for co-coordinating efforts
 - Discussion: Should there be a permanent secretariat? Should the secretariat be rotating? And can we have a secretariat that reflects our North-South make-up?

Ultimate decision: Begin with a loose interim structure and then evaluate in Toronto whether or not we need to build a more structured entity.

Friday, July 8, 2005

Toward Toronto

Betsi Pendry – “Women at Toronto”

Joyce Hunter – IAS Women’s Caucus Satellite Conference

Violeta Ross, Pat, Rung, Beri Hull, Maria de Bruyn, Marjorie Hill, Joyce Hunter, Mabel Bianco, Betsi Pendry, Julia Andino, Tyler Crone, and Ida Susser

- Participation in IAS committees
 - Conference programming
 - Violeta – Community Program
 - Beri – Leadership Program
 - Mabel – Science
 - Joyce – Abstract review
- Women at Toronto/ Network activities
 - Abstracts
 - Human rights issues such as child custody or gender based violence
 - Gender equity in treatment access
 - Gender and sexuality
 - Leadership
 - Skills-building workshops
 - Advocacy
 - Language/translation
 - Media/press
 - Funding/fellowships, bringing community based leaders to the conference
 - Collaboration with Blueprint Coalition, linking with local community
 - Louise Binder and Jennifer Kitts
- IAS Women’s Caucus Satellite Conference

Summary of Network vision and mandate

Things we hope to get:

- Women's empowerment and leadership (especially poor women and women in marginalized groups)
- Translating issues into action (regarding women and HIV)
- Diverse participation
- Joint activities
- Identify how I can be a resource/learn what others are doing
- Linkages at local level—ongoing, not dependent on conference
- Structure for effective network
- Roles and responsibilities (individual and organization)
- Build women's leadership in existing networks
- Issue priorities for human rights organizations
- Bridging feminists and HIV+ women

Actions this Network could take:

- Evidenced based advocacy
- Legal advocacy
- Make leaders of women in HIV/AIDS through voice
- Involvement of, including direct support for, grassroots actors
- Hold "town hall" style meetings on HIV/AIDS
- Communicate critical information to women
- Address cultural barriers to women's rights
- See Toronto as a platform but build at community level in countries
- Translate information up and down
- Be a means of participation
- Leadership development through recognizing our own leadership and through bringing young women forward
- Link existing entities in related fields to HIV/AIDS
- Develop a vision and a sound bite - "make it sexy"
- Set the women and HIV/AIDS agenda
- Be a response mechanism, through press conferences and press releases
- Be a watch dog entity, vigilancia ciudadana

Premise and principles of the Network:

- Gender equity
- Cultural awareness
- Grassroots, indigenous participation (representation)
- Education
- Development of power and strategies
- Involvement of youth
- Actions are impact driven
- Shared leadership and distribution of power
- Effective, clear, and consistent communication
- Good documentation
- Non-hierarchical
- Diversity – geographic and gender identity and maintaining an active consciousness about diversity
- Inclusive of multiple voices, multiple cultures, and multiple vulnerabilities
- Commitment to democracy
- Internal accountability / Accountability through transparency and good governance
- Indivisibility and intersectionality of issues and identities
- Commitment to addressing neglected and contentious issues
- Independence
- Flexible and strategic
- Support ongoing efforts – don't duplicate!
- Working with what s already in place – linking with and enhancing what is in place

- Governing bodies should “look like the epidemic”: mostly from developing

world, black and Latina women from the North

Why this Network matters:

- Bringing women to the table – defining and promoting leadership
- Linking the global with the local in meaningful ways
 - Translate every day realities into practice
- Bridging the women’s rights, sexual and reproductive rights, and HIV/AIDS communities
- Real prevention that addresses men, violence, reproductive health, gender equity

- Need more efforts to stop the pandemic among women
- Harness the momentum of the Barcelona Bill of Rights
- Intent to complement ICW
- Indivisibility of rights
- Prioritizing neglected, contentious issues
- Helping local groups do better advocacy
- Men to take leadership on gender, not just women

Appendix II

Participant List

Retreat participants:

Julia Andino, Women's Institute, GMHC, USA

Maria de Bruyn, Ipas, USA

Luisa Cabal, Center for Reproductive Rights, USA

Tyler Crone, Yale University, USA

Gregg Gonsalves, GMHC, USA

Marjorie Hill, Women's Institute, GMHC, USA

Beri Hull, ICW and the Global Coalition on Women and AIDS, USA

Joyce Hunter, Columbia University, USA

Monruedee Laphimon, Southeast Asian Consortium on Gender and Sexuality and Health,
Thailand

Lydia Mungherera, TASO, Uganda

Priya Nanda, Center for Health and Gender Equity, USA

Betsi Pendry, The Living Together Project, South Africa

Tricia Pertuney, Intern, Human Rights Watch, USA

Violeta Ross, ICW and the Global Coalition on Women and AIDS, Bolivia

Cynthia Rothschild, Center for Global Women's Leadership, USA

Nichanun Sodchuen, Thailand Network of People Living with HIV/AIDS (TNP+)

Lauren Suchman, Intern, Yale University, USA

Ida Susser, City University of New York, USA

Janet Walsh, Human Rights Watch, USA

MariJo Vasquez, ICW, Spain

Rachel Yassky, The Starfish Project - Center for Special Studies, USA

Additional Initiative participants:

Mabel Bianco, FEIM, Argentina

Louise Binder, Blueprint Coalition for Action, Canada

Edgar Carrasco, LACCASO/ACCSI, Venezuela

Nazneen Damji, UNIFEM, USA

Jodi Jacobson, CHANGE, USA

Jennifer Kitts, ACPD, Canada

Rebecca Schleifer, Human Rights Watch, USA

Tripti Tandon, Lawyer's Collective HIV/AIDS Unit, India

Alice Welbourn, ICW, UK

Appendix III

WOMEN AND HIV/AIDS: THE BARCELONA BILL OF RIGHTS

As we enter the third decade of the global HIV/AIDS pandemic, women, especially the young and the poor, are the most affected. Because gender inequality fuels HIV/AIDS and HIV/AIDS fuels gender inequality, it is imperative that women and girls speak out, set priorities for action and lead the global response to the crisis.

Therefore, women and girls from around the world unite to declare our rights and urge all governments, organizations, agencies, donors, communities and individuals to make our rights a reality.

Women and girls have the right:

To live with dignity and equality.

To bodily integrity.

To health and healthcare, including treatment.

To safety, security and freedom from fear of physical and sexual violence and abuse throughout their lives.

To be free from stigma, discrimination, blame and denial.

To their human rights regardless of sexual orientation.

To sexual autonomy and sexual pleasure.

To equity in their families and intimate partnerships.

To education and information.

To economic independence.

These fundamental rights shall include, but not be limited to the right:

To support and care which meets women's particular needs.

To access acceptable, affordable and quality comprehensive healthcare including antiretroviral therapies.

To quality mental healthcare.

To sexual and reproductive health services, including access to safe abortion without coercion.

To a broader array of preventive and therapeutic technologies that respond to the needs of all women and girls, regardless of age, HIV status or sexual orientation.

To access user-friendly and affordable prevention technologies, such as female condoms and microbicides, with skills building training on negotiation and use.

To HIV testing after informed consent and protection of the confidentiality of status.

To choose to disclose status in circumstances of safety and security without the threat of violence, discrimination or stigma.

To live one's sexuality in safety and with pleasure irrespective of age, HIV status or sexual orientation.

To choose to be mothers and have children irrespective of HIV status or sexual orientation.

To safe and healthy motherhood for all, including the safety and health of children.

To choose marriage, form partnerships or divorce, irrespective of HIV status or sexual orientation.

To gender equity in education and lifetime education for all.

To formal and informal sexual education throughout life.

To information, especially about HIV/AIDS, with an emphasis on women and girls' special vulnerability due to biological differences, gender roles and inequality.

To food security, safe water, shelter and basic sanitation.

To employment, equal pay, recognition of all forms of work including voluntary and non-coerced sex work and compensation for care and support.

To economic independence such as to own and inherit property, and to access financial resources.

To freedom of movement and travel irrespective of HIV status.

To freedom from harmful traditional practices.

To express religious, cultural and social identities.

To associate freely and be leaders within religious, social and cultural institutions.

To lead and participate in all aspects of politics, governance, decision-making, policy development and program implementation.

XIV International AIDS Conference • Barcelona, Spain • 11 July 2002

A global effort initiated by Women at Barcelona and Mujeres Adelante with lead involvement by the International Women's AIDS Caucus of the International AIDS Society and the International Community of Women Living with HIV/AIDS.

Appendix IV

Background Materials

Issue Briefs

Human Rights and Ethics

HIV/AIDS is a preventable disease, yet approximately 5 million people were newly infected with HIV in 2003, the majority of them through sex. Many of these cases could have been avoided, but for state-imposed restrictions on proven and effective HIV prevention strategies, and censorship of lifesaving information about them. Many governments around the world either fail to guarantee access to condoms, or impose needless restrictions on access to condoms and related HIV/AIDS information. State-sponsored abuse, and failure to protect the rights of marginalized people – including lesbian, gay, bisexual, and transgender men and women; sex workers; and women and girls more generally – puts such marginalized people at risk of HIV infection in the first place, and impedes their access to HIV/AIDS information, treatment, and care.

In many parts of the world, women and girls are being infected by HIV at a faster rate than their male counterparts; and in sub-Saharan Africa, women and girls constitute nearly 60 percent of those living with HIV/AIDS. The subordination of women and girls in law, custom, and practice, and structural factors of violence, abuse, and economic and social discrimination constrain the capacity of women and girls to engage in safe sexual practices, and put them at risk of HIV and impede their access to information, care, and treatment services.

Similarly, abuses against lesbian, gay, bisexual and transgender individuals, and of people working in prostitution, impedes access to information, care, and treatment. Laws criminalizing consensual sex between adults (including laws criminalizing consensual homosexual sex between adults, or sodomy laws, as well as laws criminalizing prostitution) are used to harass, arrest, and detain people based on their perceived sexual orientation, gender identity, or status as sex worker. In some cases, police themselves use the law as a tool to extort sex and/or money from lesbians and gay men, as well as sex workers, and AIDS outreach workers working with them. As a result, lesbian, gay, bisexual and transgender men and women, as well as sex workers, are often driven underground and away from HIV information and services.

In the midst of this crisis, the United States, the world's leading donor to HIV/AIDS programs, has ramped up support for unproven programs that threaten to deepen these crisis, including programs that promote sexual abstinence and marital fidelity (“abstinence-only” programs), and restrict the range of activities that can be undertaken as a condition of receiving U.S. money, including by requiring grantees to pledge opposition to prostitution and by limiting work that can be done with people in prostitution.

This initiative could effectively use its time and resources to articulate and support evidence-based HIV prevention programs and policies that go beyond the narrow ones currently being promoted by the U.S. and adopted by many bootstrapped recipients. In particular, we could all pool our resources to address the limitations of the current “ABC” approach to HIV prevention and other rights-abusive policies, including restrictions on working with sex workers. Human

Rights Watch has several resources that could be used as a starting point (see, e.g., “Dose of Reality. Women’s Rights in the Fight Against HIV/AIDS,” <http://hrw.org/english/docs/2005/03/21/africa10357.htm>; “Hated to Death: Homophobia, Violence, and Jamaica’s HIV/AIDS Epidemic,” May 18 letter to George Bush protesting restrictive policies on working with people in prostitution as threatening lives and health of sex workers, <http://hrw.org/campaigns/hivaids/hiv-aids-letter/>.)

There are many groups doing important work in this area. See, e.g., signatories to sex worker letter, on sex workers; we could provide a similar list for LGBT groups and groups working on broadening the “ABC” approach to HIV prevention. Few, however, have focused or analyzed HIV/AIDS-related abuses (of rights to information, nondiscrimination, freedom from violence, etc.) from a human rights perspective. And though there are many groups working on these issues, to date there has been insufficient coordination of the work that many of us are doing on them. The sex worker letter, of which Rebecca Schleifer, was one of the primary editors, is a recent effort to join together people from various backgrounds and communities to forge a strategy to address restrictions on working with women in prostitution among the many groups working on this issue.

Sexual and Reproductive Rights and HIV/AIDS

General themes currently being addressed

- **The right to life and health**
 - Health care issues for HIV+ women
 - gynecological care for women living with HIV
 - lack of information for most women living with HIV about their increased risks of cervical cancer and the advisability of frequent PAP smears, etc.
 - Prenatal care for HIV+ women
 - the group raised issues about framing pre-natal care in a way that empowers women and ensures that their rights are addressed
- **The right to non-discrimination**
 - Both in the conditions that make women more vulnerable to contracting HIV/AIDS--such as the prevalence of GBV--and the treatment of HIV+ women
 - Addressing the needs of women who may be subject to multiple forms of discrimination and stigmatization
- **The right to privacy**
- **The right to information**
 - The need for more research on possible interactions between hormonal contraceptives and drugs used to treat opportunistic infections and ART plus the lack of materials on contraceptives in relation to HIV (e.g., some methods are not preferred for HIV-positive women)
- **Consent and confidentiality regarding testing**
 - Issues with “provider-initiated” testing, which has been increasingly supported as a means to ensure higher rates of testing by pregnant women, can threaten

informed consent. Though UNAIDS and WHO maintain that, “for provider initiated testing . . . patients retain the right to refuse testing, i.e. to ‘opt-out’ of a systematic offer of testing,” many physicians mistakenly believe that provider-initiated testing, specifically routine offering of testing, does not require them to seek informed consent. In this way, “opt-out” testing becomes indistinguishable from mandatory testing, as women are routinely tested without their knowledge or informed consent.

- Making the provision of health care services contingent upon HIV/AIDS testing also raises serious concerns about informed and voluntary consent.
- **Mainstreaming HIV/AIDS into comprehensive health services to improve access and avoid stigma**
 - Integrating HIV/AIDS into existing family planning services
 - Ensuring that microbicides, once approved, are widely available through government health and family-planning clinics
 - Integrating RH services into existing HIV services
 - Offering EC and ARVs to rape survivors
 - Informed consent remains vital in this approach
- **The importance of a gender-sensitive approach to HIV/AIDS, trauma, and substance use**
 - There is a need to develop a comprehensive framework to work and understand women’s multiple realities, coping mechanisms, and acts of resistance.
- **The ways in which HIV/AIDS prevention policies are used, both intentionally and unintentionally, to undermine the reproductive and sexual rights of women**
 - The use of HIV/AIDS to stigmatize women’s sexuality and sexual behavior despite evidence that men’s sexual practices play a far greater role in the high prevalence of HIV, government and traditional leaders around the world have demonized and stigmatized women’s sexuality, identifying it as the key to both prevention and containment.
 - The use of the HIV/AIDS pandemic to promote abstinence only education and limit women’s access to reproductive health information and contraceptives
 - Restrictions on the right of HIV+ women to become pregnant, carry a pregnancy to term, or marry.

Issues that still need more attention:

- **Abortion**
 - Coerced abortion, access to safe and legal abortion services, access to complete and unbiased counseling about abortion and the risks of pregnancy and delivery to the health of both the woman and the fetus
- **Forced sterilization of HIV+ women**
 - The HRW report *A Test of Inequality: Discrimination against Women Living with HIV in the Dominican Republic* indicates that this practice is often used and justified as a way of preventing further mother to child transmission. ICW has also documented this in Thailand and other countries.

- Such incidents have been denounced in Chile for over 10 years. Vivo Positivo, a national network of PLWHA, has a study. In other LAC countries, denunciations of cases are frequent.
- Group raised the importance of framing this issue within the broader picture of coercive sterilization practices such as in Puerto Rico, Romania, Peru, etc.
- **The right to reproductive choice**
 - Having access to a wide range of contraceptive methods
 - Informing men about contraception and motivating them to use it
 - Emergency contraception
 - Making sure there is information about all these issues
- **The right to health care and the importance of gynecological care for women living with HIV**
- **Denial of services to HIV+ women/restrictions on services**
 - Making ART contingent on using certain contraceptive methods
 - Denial of gynecological/obstetric care for these women
 - group raised question of which countries this is occurring in—area for further research and input
 - Medical providers' denial of sexual and reproductive rights to women who partner with women.
- **Other parenting options for HIV-positive women and men**
 - Restrictions on access to assisted conception and legal adoption
- **Aspects of PMTCT programs that may violate women's rights**
 - PMTCT programs are primarily conceived of as prevention programs for infants, leaving women, their experiences, and their rights largely invisible. However, fundamental human rights are implicated in the development of PMTCT programs: the right to give informed consent, the right to confidentiality, and the right to access health care without discrimination.
- **More research on counseling, confidentiality, and informed consent surrounding HIV testing**
 - The Human Rights Watch report on the Dominican Republic exposes the multiple ways in which women's rights are violated through lack of consent and confidentiality in HIV testing.
 - Importance of drawing attention to the increased trend toward mandatory testing of women, often without counseling.
- **Development of a global advocacy plan to accelerate microbicides development and access**
 - This will entail expanding advocacy, outreach, raising awareness, and mobilization of women through leadership development and community organizing.

Existing groups, networks, institutions

- **ICASO**—International Council of AIDS Service Organizations (useful publication-- *HIV and Human Rights in a Nutshell* available at http://www.icaso.org/HIVAIDS_and_HRinNutshell-Webversion-v2.pdf)
- **CLADEM**-- Latin American and Caribbean Committee for the Defense of Women's Rights (www.cladem.org/)--working with other organizations to draft an Interamerican Convention on Sexual and Reproductive Rights
- **LACWHN** --Latin American and Caribbean Women's Health Network,
- **LACCASO**--Latin American and Caribbean Council of AIDS Service Organizations
- **Human Rights Watch** (The report on the Dominican Republic referred to above--*A Test of Inequality: Discrimination against Women Living with HIV in the Dominican Republic* –is available at [http://hrw.org/reports/2004/dr0704/.](http://hrw.org/reports/2004/dr0704/))
- **Lawyer's Collective, India** (<http://www.lawyerscollective.org/index1.htm>)
- **Forum for Women, Law and Development, Nepal** (<http://www.fwld.org.np/>)
- **Treatment Action Campaign, South Africa** (<http://www.tac.org.za/>)
- **ICW**
- **CRR**
- **Ipas**
- **Pop Council/FHI** – they are supporting testing during labor and delivery

People and networks to bring in:

- **ARROW**
- **WGNRR**
- **youth groups working on HIV/AIDS**
- **ASTRA Network (Eastern Europe) as “allies”**

Groups to whom we could send advocacy materials (op-ed pieces, fact sheets, etc.):

- **AWID's Friday Resource Net,**
- **GENDER-AIDS**
- **STIGMA-AIDS**
- **Panos**
- **group of African first ladies who are saying they want to devote more attention to HIV**
- **the People's Health Movement**

Gaps in terms of strategy or focus

More could be done to hold governments accountable under their domestic and international obligations to safeguard women's reproductive and health rights. Similarly, there is a need to raise awareness of these obligations among governments and civil society.

Content points and possible strategies for the whole group to consider for discussion, and potential adoption as activities we want to engage in.

- It would be useful to consider strategies that can help increase government accountability and raise awareness about the importance of government's meeting their human rights obligations to HIV+ women.

- **Working with international bodies towards norm setting and accountability:**
 - **Treaty Monitoring Bodies**
 - Shadow reports/letters that highlight violations against people with HIV/AIDS
 - Using individual complaint mechanisms where countries have ratified the optional protocols
 - **Use of Special Rapporteurs [Paul Hunt is interested in the issue—others such as the SR on education; Yakin Erturk on Violence]**
 - **Working with inter-agency groups** to support their development of HIV/AIDS norms that fully address human rights issues
 - **Working with the FIGO and regional associations** to flesh out protocols on informed consent to help better define what provider-initiated testing would look like
 - **Regional bodies:** For example, the Inter-American Commission on Human Rights has held hearings on access to comprehensive HIV care, including ARVs. It has ordered “precautionary measures” to ensure access to ARVs in El Salvador, Ecuador, the Dominican Republic, Peru, Bolivia, Nicaragua, Guatemala, Chile, and Honduras. Exploring the use of the European Court of Human Rights and, once it is established, the African Court of Human Rights.
- **Accountability and standard-setting through National judicial systems:**
 - **Bringing cases to national ombudsmen/human rights commissions**
 - **The use of the constitutional remedy of *amparo*** in various Latin American countries to secure court orders compelling the government to provide HIV/AIDS treatment could also be examined.
 - In 1999 in *Cruz Bermudez, et al v. Ministerio de Sanidad y Asistencia Social (MSAS)*, the Venezuelan Supreme Court reiterated the State’s positive obligations regarding the right to life and health and held that the MSAS must provide the HIV+ plaintiffs with the necessary medical treatment, including ARVs.
 - Promoting more cases related to women's health and prevention. In Argentina in 1997, eight NGOs did an *amparo* for access to treatment and succeeded but there has been no legal action related to prevention.
 - **Other litigation:** The South African High Court in Transvaal has also issued a decision affirming the government’s duty to provide PMTCT services, and that these services must protect the rights of both mother and child. (*Treatment Action Campaign, Dr. Haroon Saloojee, Children’s Rights Centre v. Minister of Health and Others*, South Africa, High Court, Transvaal Provincial Division, CCT 8/02, Case No. 21182/2001)

Gender Equity in Access to Care, Treatment, and Support

Key concerns:

1. The inclusion of specific needed sex/gender/age disaggregated data in the reporting system to 3 by 5 from each of the country.
2. The relationship between the US funding restrictions on working with sex workers and access to treatment.
3. Women's property rights and access to treatment
4. Religious or cultural traditions and policies that interfere with women's access to treatment (e.g. polygamy).
5. Access to sexual, reproductive health, and family planning services and access to treatment.
6. The disincentive to seek treatment because of the new emphasis on opt-out testing and the risk of gender violence, abandonment, loss of property, livelihood, and access to children which may be the result of a positive diagnosis.
7. The need for gynecological care for women with HIV.
8. The need for specific treatment outreach programs to recruit women into care, particularly in rural settings.
9. Gender violence and access to treatment.
10. Innovative models of service delivery.
11. Interface between disclosure and access to treatment a big problem. For example, if a woman chooses not to breast-feed an infant she immediately arouses suspicion regarding her HIV status.

Participant Survey

ACTING ON RIGHTS: THE WOMEN AND HIV/AIDS LEADERSHIP RETREAT PARTICIPANT QUESTIONNAIRE

Prior to the retreat, we are defining and assigning tasks so that we bring together our knowledge, energy, and experience in a focused and powerful way. This list of questions is intended to document our respective perspectives; to identify opportunities for collaboration and partnership; to assess our priorities; and to analyze our strengths.

We hope that each of you will respond in as much depth as you are able and return the completed questionnaire by **June 27, 2005** so that the responses can inform the final agenda for the retreat and be a building block in our collective efforts. Please note that responses will be name identified, compiled, and shared with the group. This is a long list so we appreciate your thought and attention. Questions 1-7 are the most important for us to get your responses in advance of the meeting. THANK YOU!

1) Who are you?

- What is your background?
- What do you currently do?
- What do you wish you were doing?

2) Goals and Objectives for the Retreat:

- Why are you attending this retreat?
- What do you hope to achieve?
- What don't you want from the retreat?
- What would you like to have included in the agenda?
- Is there a workshop or discussion that you would like to lead?

3) Goals and Objectives for Launching a New Initiative:

- In what way will participation/membership in a new network focused on gender, human rights, and women's leadership in the global fight against HIV/AIDS be beneficial to you?
- Please describe, for yourself, what you are seeking from the new network.
- In what ways will it help you perform your work better?
- If you are part of an existing organization or network, in what ways does it already meet your needs? How could a new network enhance or complement the activities of these existing organizations?
- What don't you want from a new network?

4) Building a New Initiative:

- In what ways could you concretely contribute to developing a new network?
- What role would you like to play in such an effort?

5) Form and Structure:

- What is the most appropriate mechanism for this collaborative work?
- How do we ensure that it is participatory and representative?
- How do we ensure that it is sustainable?
- How do we connect to and build upon existing work and entities?
- What should be our mission?

- What should be our name?

6) Building Partnerships:

- What are the relevant networks, coalitions, and organizations in your country/region?
- What are the entities to which you belong – such as organizations, networks?
- To launch a new network, with whom (people and organizations) would you collaborate? In the short term? In the longer term?

7) Identifying Priorities:

- Please list and rank priority issues for attention in your community, country or region that you would like for this initiative to address.

8) Leadership and Participation:

- What mechanism is needed to ensure women’s participation and leadership, especially that of women living with HIV/AIDS?
- Who are the key leaders in your community, country and region?
- How do we make the issue of leadership and participation an integral part of our efforts?

9) Linking Reproductive and Sexual Rights to HIV/AIDS:

- What are the critical issues at this intersection?
- How do we keep sensitive issues on the table?
- How do we build bridges with the women’s rights community and the sexual and reproductive health and rights community?
- Does law matter?
- How does this nexus of issues relate to the other thematic working groups?

10) Human Rights in Prevention and as Prevention:

- What are the critical issues at this intersection?
- With the increasing attention to rights-based responses, what does this mean and how is it relevant to women and girls infected and affected by HIV/AIDS?
- Is advancing human rights a means of prevention?
- Does law matter?
- How does this nexus of issues relate to the other thematic working groups?

11) Gender Equity in Access to Treatment, Care, and Support:

- What is the wedge issue around which we can build a broad campaign?
- What are the questions/challenges for:
 - Women and girls living with HIV/AIDS
 - Providers
 - Researchers
 - Policy makers
- How does this nexus of issues relate to the other thematic working groups?

Appendix V

History of a Movement

Informal History of the International Community of Women Living with HIV/AIDS

From Maria de Bruyn: A decision was made to hold the 1992 8th International AIDS Conference in Amsterdam after people refused to accept a conference proposed for Boston due to US restrictions on allowing in people living with HIV/AIDS. The decision was made rather late and this may have been the conference with the shortest preparation time ever. Jonathan Mann, co-chair of the conference, was adamant that human rights and community participation – especially including people living with HIV/AIDS – would be a key theme of the conference.

At that time, a group of women living with HIV/AIDS in The Netherlands wanted to establish connections with other HIV-positive women around the world. The women's group of the HIV Association and members of Act Up! The Netherlands proposed holding a pre-conference meeting that would unite positive women and also help prepare them for navigating the conference since many women would have never attended such a large meeting before.

The women who were key drivers of the initiative/meeting included: Anita Bolderheij, Esther Nederhoed, Jeannine van Woerkum and Hannah Jansen. They asked a few HIV-negative women to help them in the preparations; they included Jeannette Sloodbeek (now a consultant on HIV/AIDS and youth programs) and myself. Sadly, Anita, Esther and Jeannine are no longer with us; Hannah is still going strong. She is the very proud mother of two wonderful children and still supports other women living with HIV in The Netherlands. I was privileged to supervise her M.A. thesis which, to my knowledge, is the only thesis written about HIV-positive women by a positive woman in The Netherlands. Hannah graduated cum laude as an anthropologist.

The pre-conference meeting took 2.5 days (if I remember correctly) and included 56 women living with HIV from 27 countries around the world, except for a few sessions facilitated by other women. For example, since I was on the Community Liaison Committee for the International AIDS Conference, I did a session with the women on how to choose sessions that were relevant to women, how sessions were organized, how to best present questions during Q&A, etc.

ICW was established at that meeting by a group of about 40 women. They chose women to lead the effort – including Jo Manchester & Kate Thomson (UK), Beverly Greet (Australia), Patricia Pérez (Argentina – currently ICW LA contact person) and Cindy Robins (USA). Beverly and Hannah worked on the 10 goals of ICW. Some women volunteered to be regional contact persons (e.g., Dorothy Onyango from Kenya, who is still with WOFAK). The presentation of ICW was wonderful – all the women, including a few they met during the conference, mounted the stage during the closing ceremony and called out the country they were from. Many of these women had not yet come out publicly in their own countries – and there they were being filmed on TV! It was a very emotional moment and the start of a unique organization/network.

ICW organized a meeting for 50 positive women in Hamburg, Germany, in 1993. It has had its ups and downs over the years and there have been times when it was difficult for them to run their central hub office. It is now doing very well and it's great that they are going to be a part of our new advocacy and action network!

Informal History of the International AIDS Women's Caucus

From Joyce Hunter: The International AIDS Women's Caucus (IAWC) was formed in Amsterdam in 1992 at the VIIIth International Conference on AIDS by women affected by the epidemic who met together because they felt that women's issues were not being adequately addressed at the conference. Our goal at that time was to ensure that women's issues would be highlighted at future World AIDS Conferences. Also at that time, IAWC was officially accepted as a Caucus of the International AIDS Society.

IAWC, working closely together with the International Community of Women Living with HIV/AIDS, (ICW) organized satellite meetings at each World AIDS Conference held since 1992 (Berlin, Yokohama, Vancouver, Geneva, Durban, Barcelona, Bangkok Conferences). IAWC has also met with IAS leadership at every World AIDS Conference to gain support and resources for the Caucus, as well as urge IAS to make women's HIV issues and rights more visible in its work. IAWC representatives have also served as members of scientific and other conference tracks and conference abstract committees promoting women's participation in the Conferences.

The group has been a network of interested women and has emphasized networking at the regional level (regions: Africa, Europe, Asia/Pacific, Latin America/Caribbean, and North America), and preparing for programs at international conferences. Working closely with ICW and other organizations (i.e., American Foundation for AIDS Research (amfAR), International Center for Research on Women (ICRW), Global AIDS Action Network (GAAN), the Global Alliance for Africa, Latin American and Caribbean Women's Health Network (LACWHN), NAPWA-South Africa, Society of Women and AIDS in Africa (SWAA), UNIFEM) IAWC has promoted regional networking at and between international conferences.

Caucus meetings have also been held at semi-annual Biopsychosocial Conferences, Microbicides Conferences, and other venues (i.e., the Pan Am Women's Leadership Conference in Buffalo, NY, 2000). IAWC was also represented at Beijing and Beijing + 5 and +10 UN Conferences, as well as the International Conference on Population and Development (Cairo) and ICPD +5 and +10 process at meetings of the UN Commission on the Status of Women held in New York City.

The IAS Newsletter, No. 9, March, 1994, was written by IAWC representatives and devoted to HIV/AIDS and women's issues. Similar articles have been published in additional IAS Newsletters (1996, 2000), and the South African Journal, AGENDA (2000). In addition, IAWC co-sponsored a pre- and post-conference discussion on the Gender AIDS list serve.

In planning for the 2000 Durban World AIDS Conference, we were joined by members from GMHC's Family Services (now the Women's Institute) and a group of feminists worldwide interested in gender and HIV issues. In addition to planning for the Women's Satellite Meetings in Durban, the "Women at Durban" committee planned a parallel program of workshops in and for Durban and the surrounding communities. For the Barcelona Conference, the IAWC participated in the project Women at Barcelona developing activities inside and outside the Conference, producing the Barcelona Bill of Rights. IAWC with ICW and other groups participated in the women's demonstration at the closing ceremony, obtaining the recognition of women's issues in the closing remarks by President Clinton.

In Bangkok, with the Thai Women's Task Force, ICW and UNIFEM, the Caucus participated in the women's leadership group and developed workshops in the Global Village. The Caucus will continue networking and promoting women's and HIV rights and needs.

Appendix VI

Women's Networks / Coalitions List

Compiled by HRW Interns – June 2005

African Women's Development and Communication Network (FEMNET)

Contact Information:

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Basic Mission: The African Women's Development and Communication Network (FEMNET) was set up in 1988 to share information, experiences, ideas and strategies among African women's non-governmental organizations (NGOs) through communications, networking, training and advocacy so as to advance women's development, equality and other women's human rights in Africa. FEMNET aims to strengthen the role and contribution of African NGOs focusing on women's development, equality and other human rights. It also aims to provide an infrastructure for and a channel through which these NGOs can reach one another and share information, experiences and strategies to as to improve their input into women's development, equality and other women's human rights in Africa.

Materials Produced/Provided: FEMNET has authored many publications and reports over the years on workshops, events, and issues pertaining to African women and development. They also produce a bi-annual newsletter.

Funding: FEMNET receives support from ActionAid, The EU, the German Cooperation Development, the Swedish International Development Association, UNIFEM, UNDP, the Ford Foundation, Heinrich Boll Foundation, UNHCR, Emory University, the African Women's Development Fund, and the General Board of the Global Ministries of the United Methodist Church

Organizational Notes:

- FEMNET is governed by a Constitution and the following governance and administrative structure:
 - National focal points in 22 African countries whose representatives attend a tri-annual programming conference and General Assembly.
 - An elected 11 member Executive Board which includes two Board members per sub-region and a Chairperson. In addition, there are two Ex-Officio Board members (immediate past Chairperson and the Executive Director).
 - An elected seven member Board of Trustees to oversee FEMNET's assets.
 - Secretariat which implements FEMNET's programmes and is headed by an Executive Director.

Association for Women's Rights in Development (AWID)

Contact Info:

Toronto Secretariat:

215 Spadina Ave., Suite 150,

Toronto, Ontario

M5T 2C7

CANADA

T: (+1) 416-594-3773

F: (+1) 416-594-0330

Email: awid@awid.org

Membership Info: membership@awid.org

Website: www.awid.org (Note: Contact information for regional offices available at the website)

Basic Mission: AWID's mission is to connect, inform and mobilize people and organizations committed to achieving gender equality, sustainable development and women's human rights. An international membership organization, AWID connects, informs and mobilizes people and organizations committed to achieving gender equality, sustainable development and women's human rights. Our goal is to cause policy, institutional and individual change that will improve the lives of women and girls everywhere. We do this by facilitating ongoing debates on fundamental and provocative issues as well as by building the individual and organizational capacities of those working for women's empowerment and social justice.

Materials Produced/Provided: News and announcements; Members can publish articles, photos, research, calls to action, links, or anything pertaining to Women's Rights in Development.

Funding: AWID's work is made possible primarily through donations from foundations and government agencies, and are registered in the United States of America as a 501 (c) (3) organization and classified as a public charity under section 509 (a) (2) of the Internal Revenue Code. There is also an annual membership fee, except for people with an annual income is less than US \$10,000, for whom membership is free.

Organizational Notes:

- AWID has approximately 5,700 individual and 150 institutional members.
- AWID is run by a board of directors and staff.
- The goals of AWID are to inform, connect, and mobilize.

INFORM through research into critical issues, with publications that advance knowledge and set out best practices, by posing important questions and by helping you stay up to date in an ever-changing world.

CONNECT at our international Forum, and by providing a virtual forum via our website and e-lists. We strengthen links among our members and connect your organization with what others are doing around the world.

MOBILIZE our members and the public by speaking up in the media and promoting a feminist agenda at important regional and international meetings, by tackling burning issues with innovative campaigns, by giving you information and tools to fuel your activism, and by celebrating our victories along the way. The current campaigns are divided in five different content themes: Feminist Movements and Organizations, Young Women and Leadership, Gender Equality and New Technologies, Women's Rights and Economic Change, and Women's Human Rights Network..

Center for Women's Global Leadership/Sixteen Days Campaign

Contact Info:

60 Ryders Lane, New Brunswick, NJ 08901-8555 USA

Tel: (1-732)932-8782

Fax: (1-732)932-1180

E-mail: cwgl@igc.org

Website: <http://www.cwgl.rutgers.edu> Tel: (1-732)932-8782

Fax: (1-732)932-1180

E-mail: cwgl@igc.org

Basic Mission:

CWGL is a consortium of six women's programs at Rutgers University created to study and promote how and why women lead, and to develop programs that prepare women of all ages to lead effectively.

Sixteen Days Campaign has international participation for 16 days of discussion, advocacy, and awareness-raising about eliminating violence against women and gender-based discrimination.

Funding: CWGL is affiliated with Douglass College at Rutgers at the State University of New Jersey, and is funded and run as an academic program.

Notes: The Sixteen Days Campaign has a coordinator based in CWGL, aided by staff and volunteer support, as well as UN agencies and other agencies focused on gender issues.

Organizational Materials Produced/Provided:

- Women at the Intersection: Indivisible Rights, Identities, and Oppressions (Publication)
- Women at the Intersection of Racism and Other Oppressions: A Human Rights Hearing (Video & Study Guide)
- Supplementary Resources Guide
- The Sixteen Days Website also provides reports and statistics gathered from outside sources to raise awareness about violence against women.

Central and Eastern European Women's Network for Sexual and Reproductive Health and Rights (ASTRA)

Contact Information:

Federation for Women and Family Planning, Wanda Nowicka

Ul. Rabsztyńska 8, 01-140 Warsaw, Poland

Ph/fax: 48.22.632 0882, 631 0817

e-mail: polfedwo@waw.pdi.net

Basic Mission: ASTRA, a new network of activist organizations in Central and Eastern Europe, was established in December 1999. Its main objective is to promote women's sexual and reproductive health and rights in the region and to ensure a prominent place for these issues on national and regional agendas.

Materials Produced/Provided: N/A

Funding: N/A

Organizational Notes:

- Linking 23 organizations from 15 different countries, ASTRA is the only network focused on sexual and reproductive health and rights in Central and Eastern Europe.
- ASTRA hopes that the Network's activities will strengthen cooperation between its member organizations, thus building our capacity to effectively achieve our goals, while also bringing the attention of the international community to our strengths and skills. In this way we hope to make a meaningful contribution to international and regional activities that address women's sexual and reproductive health and rights.
- Planned activities of the ASTRA Network include:
 - influencing national, regional and international activities associated with the Beijing +5 review;
 - information generation and sharing both within the network and beyond;
 - cooperation to improve legislation and policy at the national level;
 - implementation of joint projects at the national and regional levels;
 - training and capacity building activities;
 - creation of a database of regional resources and capacity.

Development Alternatives with Women for a New Era (DAWN)

Contact Info:

Dawn Secretariat

PO Box 13124

Suva, Fiji

Tel/Fax: (679) 314 770

Email: admin@dawn.org.fj

Steering Committee: <http://www.dawn.org.fj/about/steering.html>

Basic Mission: DAWN has the goal of world where inequality based on class, gender and race is absent from every country and from the relationships among countries; where basic needs become basic rights and where poverty and all forms of violence are eliminated. They also have the goal of institutions being open to participatory democratic processes, and where women share in determining priorities and making decisions. This political environment will provide enabling social conditions that respect women's and men's physical integrity and the security of their persons in every dimension of their lives.

Materials Produced/Provided: DAWN publications, fact sheets, and the “DAWN Informs” newsletter

Funding: N/A

Organizational Notes:

- DAWN is governed by a steering committee (also known as their “secretariat”), which is made up of the present and immediate past General Coordinators, Regional Coordinators (currently 7) and Research Coordinators (3).
- The Steering Committee meets once a year.
- Research Coordinators are responsible for coordinating research, analysis and advocacy work on DAWN's chosen themes and work closely with one another. They also work closely with Regional Coordinators, who are their vital links with issues, developments, people and networks in the different regions.
- Regional Coordinators serve as catalysts for programs of research, communications and advocacy that reflect regional priorities and are linked to DAWN's global research themes.

UNAIDS Global Coalition on Woman and HIV

Contact Information:

(No Mailing Address)

Website: <http://womenandaids.unaids.org/>

Email: womenandaids@unaids.org

Basic Mission: The Global Coalition on Women and AIDS (GCWA) is a worldwide alliance of civil society groups, networks of women with HIV and AIDS, governments and UN organizations. The Coalition works at global, regional and national levels to highlight the impact of AIDS on women and girls and mobilize actions to enable them to protect themselves from HIV and receive the care and support they need.

Materials Produced/Provided: The Coalition has produced a large number of comprehensive reports on issues pertaining to women and HIV/AIDS around the world, and created a number of Country Fact Sheets. They also provide speeches, presentations, and UN publications.

Funding: GCWA is funded by the United Nations as a body working under their auspices.

Organizational Notes:

- Run by a Global Steering Committee that includes 20-25 leaders from a range of different constituencies including UN agencies, civil society, celebrities, the public sector and academics.
- Steering Committee divides members into those who focus on global issues, and those who focus on regional issues.
- The Steering Committee meets once a year, but promotes the mission of GWCA throughout their outside work and publicity.

GROOTS International

Contact Information:

249 Manhattan Avenue
Brooklyn, NY 11211
USA
Telephone: (718) 388-8915
Fax: (718) 388-0285
Email: grootsss@aol.com

Basic Mission: GROOTS was launched in 1989 by 20 community leaders from around the world who planned a global network to support grassroots women's organizations working across national and regional boundaries, sharing resources, information, and experiences and collectively forging and consolidating a grassroots women's presence and perspective.

Materials Produced/Provided: GROOTS International produces regular policy and issue papers and articles.

Funding: GROOTS has received support from international and local agencies, private donations and in-kind contributions. Among the most recent are: the Ford Foundation, Novib, the United Nations Development Program (SUTCDC, GIDP, and UNIFEM), the United Nations Commission on Human Settlements, the Stanley Foundation, and the Methodist Board of Global Ministries.

Organizational Notes:

- GROOTS operates as a flexible network linking leaders and groups in poor rural and urban areas in the South and the North. To nurture relationships of mutual support and solidarity among women engaged in redeveloping their communities, the network is open to grassroots groups and their partners who share a commitment to four basic goals:
 - To strengthen women's participation in the development of communities and the approaches to problem solving.
 - To help urban and rural grassroots women's groups identify and share their successful development approaches and methods globally.
 - To focus international attention on grassroots women's needs and capabilities.
 - In recognition that member groups give first priority and most of their time to strengthening women's local efforts, GROOTS strategies and plans are designed to complement and upscale development, training, organizing and advocacy activities already underway.
- GROOTS International has 17 member groups and 2 partnering networks.

Huairou Commission

Contact Information:

249 Manhattan Ave.
Brooklyn, New York 11211-4905
United States
Tel: 1-718-388-8915
Fax: 1-718-388-0285
Email: jan.peterson@huairou.org
Jan Peterson
Chair of the Secretariat

Basic Mission: Forging strategic partnerships to advance the capacity of grassroots women worldwide to strengthen and create sustainable communities.

Materials Produced/Provided: The Huairou Commission periodically produces papers on issues concerning grassroots women, case studies, and also newsletters about the network's activities.

Funding: N/A

Organizational Notes:

- Since its inception, the Huairou Commission has used two organizing strategies:
 - Coalition-building and networking across networks

- Forging strategic partnerships for education, advocacy, policy dialogue and program alliances.
- The Huairou Commission is organized into a governing Council, a group of professional Partners, a group of Strategic Planners, and general Staff.
- Council (10 members): The council is Huairou’s governing/policy-setting body and includes representatives of global networks and partner groups. Each network identifies its own representatives.
- Partners (5 members): Professional partners are used here to designate those people who contribute their professional expertise to Huairou.
- Strategic Planners (9 members): Grassroots organizations are characterized by change. As conditions or issues in their communities shift; so must they. Huairou, with its allegiance to the daily lives of those on the ground, informally incorporates representatives of emerging or new-to-Huairou organizations in its planning processes.
- Staff (4): Huairou staff is composed of paid personnel, interns and a number of professional volunteers.

International Community of Women Living with HIV/AIDS

Contact Info:

Unit 6, Building 1
 Canonbury Yard
 190a New North Road, London
 N1 7BJ
 United Kingdom
 Tel: +44 20 7704 0606
 Fax: +44 20 7704 8070
 email: info@icw.org

Website: www.icw.org (Note: Regional offices contact information on the website)

Basic Mission: ICW is an international network run for and by HIV positive women that promotes all our voices and advocates for changes that improve our lives.

Materials Produced/Provided: ICW offers articles, workshops, briefing papers, images, an “HIV Survival Kit” for women with HIV, and “ICW News,” their newsletter.

Funding: ICW currently receives corporate, government and NGO funding from the donors, and accept individual donations as well.

Organizational Notes:

- Four staff members run our coordinating office in London.
- The office keeps in contact with eight Regional Contacts, seven of whom are trustees - unpaid women with HIV from around the world.
- These Key Contacts cover five regions: Africa, Asia/Pacific, Latin America/Caribbean, North America, and Europe.
- An international Board of Trustees based in London has financial and legal responsibilities for ICW (Link to Trustees page)

International Women’s Health Coalition

International Women's Health Coalition
 333 Seventh Avenue, 6th floor
 New York, NY 10001
 Tel: 212-979-8500
 Fax: 212-979-9009

Basic Mission: IWHC works to generate health and population policies, programs, and funding that promote and protect the rights and health of girls and women worldwide.

Materials Produced/Provided: IWHC offers a research library on articles and resources regarding women's health. They also provide fact sheets, reports, speeches, news, and workshop summaries.

Funding: IWHC is funded through an annual budget of \$5-6 million, provided by private foundations, UN agencies, European governments, individuals, and corporations.

Organizational Notes:

- IWHC deals with four main topics, all addressed regionally: youth health and rights, access to safe abortion, sexual rights and gender equality, and women and HIV.
- IWHC is led by a Board of Directors. Chaired by Kati Marton, the 19 members include health, human rights, legal and other professionals; philanthropists; and feminist leaders; from Argentina, Colombia, England, France, the Netherlands, India, Mozambique, South Africa, and the United States.
- Staff: President Adrienne Germain leads 25 staff who speak seven languages and have expertise in public health, evaluation, advocacy, development, and communications.

Latin American and Caribbean Women's Health Network (LACWHN)

Contact Information:

Simón Bolívar
3798, Ñuñoa
Cód.Postal: 6850892
Casilla 50610, Santiago 1,
Santiago, Chile
Tel.: (56-2) 223 7077
Fax: (56-2) 223 1066
secretaria@reddesalud.org

Basic Mission: The Latin American and Caribbean Women's Health Network, LACWHN, is a network of organizations and individuals in the women's health movement working to promote women's health and the full exercise of women's human rights and citizenship through the cultural, political and social transformation of our region and the world from a feminist perspective.

Materials Produced/Provided: LACWHN publishes Women's Health Journal, a quarterly magazine, as well as an annual publication of in depth analysis of priority issues.

Funding: N/A

Organizational Notes:

- The Latin American and Caribbean Women's Health Network unites hundreds of organizations and individuals from a wide range of nationalities, ethnicities, social backgrounds, ages, religious beliefs and sexual orientations. Numerous national and international networks also have joined forces with LACWHN. This wealth of perspectives and approaches is a fundamental strength of our organization which has grown steadily during 20 years of operation.
- Most LACWHN members are groups and individuals in the Americas (North, South and Central) and the Caribbean, but membership is by no means limited to this region. In the Americas, the countries with the greatest number of LACWHN members are Argentina, Chile, Brazil, the United States, Mexico and Peru.
- LACWHN functions through a Coordinating Office, currently based in Santiago, Chile, and a Board of Directors composed of prominent women's health activists working in Latin America and the Caribbean. The Board of Directors formulates the Network's strategies and policies and monitors and evaluates the Network's activities.

- While the board members are not national representatives, they have extensive experience in the women's health movement and are closely linked to the movement in their respective countries.
- In addition, an Advisory Board recently was established to allow past board members and the former General Coordinator of the Network to continue to share their wisdom and experience in advocacy and activism for women's health and to support the work undertaken by the Board of Directors.

Women's Funding Network

Contact Info:

1375 Sutter Street, Suite 406,
San Francisco, CA. 94109 USA
Telephone: 415.441.0706
www.wfnet.org

Basic Mission: As a worldwide partnership of women's funds, donors, and allies committed to social justice, the Women's Funding Network seeks to ensure that women's funds are recognized as the "investment of choice" for people who value the full participation of women and girls as key to strong, equitable, and sustainable communities and societies.

Materials Produced/Provided: Runs annual conference, provides tools for measuring growth and success in business and NGO endeavors, pools funds from women's organizations. Also teamed up with Women & Philanthropy to produce the two reports entitled "Making a Difference: New Wealth, Women & Philanthropy: Partnerships for Supporting Women & Girls" and "Donor Circles: Launching and Leveraging Shared Giving." Has an online "knowledge center" of women's issue related publications.

Funding: N/A

Organizational Notes: WFN is guided by a Board and run by a full staff.

Women's Global Network for Reproductive Rights

Contact Info:

Vrolijkstraat 435-D
1092 TJ Amsterdam
The Netherlands
Website: www.wgnrr.org

Basic Mission: The Women's Global Network for Reproductive Rights is an autonomous network of groups and individuals in every continent who aim to achieve and support reproductive rights for women. Their aim is to contribute to improving women's RSHR through an informed, supported, active and connected membership able to keep and bring women's Reproductive and Sexual Health Rights on the agenda of national governments, international bodies, civil society organizations and the private sector.

Materials Produced/Provided: WGNRR runs several campaigns which include news, reports, fact sheets, and petitions. They also write a newsletter and have an annual report.

Funding: N/A

Organizational Notes:

- The WGNRR website is a networking tool, and members can share in this space their organizational profile, their current projects and actions and conference and project reports as well as interesting articles and attend an annual members meeting
- WGNRR's structure consists of members, subscribers, supporters, the National Board and an International Board.

- It is represented through its Amsterdam-based Coordination Office (CO) which consists of a small team with a strong presence of interns and volunteers. The CO has expertise and a coordinating, facilitating and formal representational role.

**ACTING ON RIGHTS:
THE WOMEN AND HIV/AIDS LEADERSHIP RETREAT
6-8 JULY 2005, YALE LAW SCHOOL**

For more information on materials presented in this report, please contact Tyler Crone
(etc@aya.yale.edu).